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Barriers to family planning among women with severe mental illness

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by

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Abstract

Background: Limited attention has been paid to family planning among women diagnosed with severe mental illness (SMI) since the deinstitutionalization of this population more than 50 years ago. Overall, the few existing studies on the reproductive health of women with SMI suggest a potential unmet need for family planning education, counseling, and contraceptive services.

Objective: We explored the family planning perspectives, experiences and needs of women diagnosed with serious mental illness (SMI).

Methods: We interviewed 17 English-speaking women aged 18-55 with previously diagnosed serious mental illness who were currently receiving treatment at an outpatient community mental health clinic associated with a large safety net hospital in Atlanta, Georgia. We conducted in-depth, in person interviews, lasting 30-90 minutes, with semi-structured guides. We defined SMI as: major depressive disorder (MDD) with or without psychotic features, bipolar disorder with or without psychotic features, post-traumatic stress disorder (PTSD), schizophrenia or schizoaffective disorder[1]. Two investigators analyzed key codes and themes which emerged from the qualitative data using MAXQDA software.

Results: The most common diagnoses were major depressive disorder and post-traumatic stress disorder among the 17 women who participated in the qualitative interviews. Of the participants interviewed, 8 had more than one diagnosis. The most common type of contraception ever used was condoms with (94%), followed by oral contraceptives (88%); only 23% had ever used LARC (long acting reversible contraception). Several themes have emerged from our analysis: 1) pregnancy intention 2) pregnancy decision-making, 3) pregnancy coercion, 4) access to reproductive care and 5) barriers to reproductive care. The first three themes were influenced by both the women and partner’s attitude toward the pregnancy and often by the woman’s feelings toward her partner. The remaining themes established an unmet need for reproductive care among women with SMI seeking regular follow up with their mental health provider in addition to a general gap in psychiatric providers addressing reproductive care.

Conclusions: The findings raise important questions regarding unintended pregnancy, pregnancy decision making and partner dynamics. There is also a clear reproductive healthcare gap among these women who desire more access to reproductive healthcare but don't always know where or how to receive it in addition to it not being addressed by their mental health providers. These themes suggest an unmet need for reproductive care in this population and an opportunity for family planning providers to partner with colleagues in psychiatry to help address these needs. Furthermore, there is a need to recognize and address partner coercion as well as a need to empower women with SMI to make their own decisions.

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Chapter 1: Introduction

Background:

There has been limited attention to family planning among women diagnosed with severe mental illness (SMI) since the deinstitutionalization of this population more than 50 years ago. Due to changes in the healthcare model within this population, people with schizophrenia, bipolar disorder, schizoaffective disorder, and personality disorders which fall under the classification of SMI are far less likely to be institutionalized but rather treated in the outpatient setting[2]. This outpatient model centers on patient adherence to close follow up, compliance with effective antipsychotics, and a strong working patient-provider relationship built upon trust and communication[2, 3]. Not only does this allow for increasing independence and socialization but also substantial patient autonomy, which can be beneficial for their long-term prognosis and quality of life. However, with this autonomy, there are more opportunities for relationships that may become intimate or sexual, which ultimately can affect reproductive health[2, 4].

Research on women’s mental health generally focuses on more common disorders such as anxiety and depression. Rates of anxiety and depression are higher than 60% of the population and are often concomitant among people[5]. Not only are anxiety and depression more prevalent in women than men but these diagnosis account for one of the leading causes of disability worldwide[5]. Mental illnesses tend to affect women who are less educated, poor and unemployed. Additionally, these women tend to go undiagnosed and are therefore less likely to receive treatment[5].

While there has been a paucity of research on the family planning outcomes of women with SMI, there is some literature which suggests that the rates of sexual activity are the same for this population as compared to women without SMI [6] . However, despite the treatment model changing in this population in the last half century, there continues to be little to no attention on how sexual activity and its ramifications affect women with SMI. Some of the earliest studies about family planning outcomes on women with mental illness were conducted just as the treatment paradigm began to shift toward outpatient treatment demonstrated that less than 5% of women with psychiatric diagnoses were using contraception [7]. Studies conducted nearly thirty years later, showed that despite the majority of women with SMI being treated as outpatients with more independence and autonomy, the rates of contraception had not changed significantly[8]. One study showed how infrequently women discharged from a psychiatric hospital were asked about their sexual activity and/or contraceptive plan[8]. In many cases, their relationship status or gravidity and parity were not discussed either on admission, during their stay or upon discharge. Several studies demonstrated that information addressing topics such as contraception and sexual activity were simply not addressed during inpatient psychiatric hospitalizations [7, 8]. While the significance of these topics in reproductive aged women who are sexually active is paramount, one study demonstrated why this topic is significant. 80% of the women discharged home from a mental hospital were started on medications with teratogenic or unknown side effects in pregnancy[8]. Despite the potentially devastating affects these medications could have on a pregnancy, there was no documented discussion about contraception and reproductive plans [8]. While understudied, there is some data suggesting that women with SMI may have lower uptake of contraception [8]. Similar to the general population, women with more common disorders such as anxiety and depression, are more likely to use user dependent methods such as oral contraception and condoms [3] but there is little data on women with psychotic disorders or SMI.

Previous research suggests that people with SMI have poor insight into their mental health disorder and its impact on sexual behavior. Several studies have suggested that individuals with SMI are more likely to participate in high risk sexual behaviors, potentially involving drug use, unprotected intercourse, casual sexual encounters or trading sex for money[9]. These behaviors may demonstrate a vulnerability within this population for sexual exploitation due to a possible decreased ability to negotiate safer relationships or issues compromising their capacity such as coexisting substance abuse issues [9]. It is reasonable to hypothesize that women with SMI experience an even higher risk of unintended pregnancy given reduced cognitive processing, limited decision-making capacity, and potentially reduced reproductive autonomy, all of which may impact their sexual and contraceptive decision-making and behaviors[3]. Because of this, women with SMI may be more likely to become pregnant unintentionally because of risky and negative sexual experiences as compared to women without SMI [4].

Recent studies on the intersection of mental and reproductive health have focused on common mood disorders, but there has been little research on the factors influencing unintended pregnancy in the context of SMI. There is some suggestion that the support a partner provides women with SMI may play an important role in pregnancy intendedness, prevention and planning [10]. Research has demonstrated that a women’s relationship with her partner can have an effect on perinatal mental health [10] and that women with SMI often have partners who are also living with SMI. These partners may also have higher rates of risky health behaviors thus demonstrating possible increased susceptibility for both women with SMI and their partners to social and psychological vulnerabilities [10]. A better understanding of the family planning experiences and needs of this at risk population, including factors influencing decision-making and behaviors around sex, contraceptive method use, and receipt of family planning services, is needed to inform more effective, holistic, and patient-centered models of women's health care.

Proposed research:

Given the limited research on women with SMI, this study sought to explore the knowledge gap in this area using semi-structured, in-depth interviews. This study sought to describe the family planning experiences and needs of women with diagnosed SMI seeking outpatient psychiatric treatment in an urban mental health outpatient clinic in order to identify the multi-level barriers to reproductive healthcare and contraceptive use that contribute to unintended pregnancy risk among this group. This research is innovative and will contribute uniquely to the work on mental health and family planning in several major ways, as it will provide: 1) Specific nuanced information on the multi-level facilitators and challenges of seeking and/or receiving family planning care faced by women with SMI, including their perceived unmet contraceptive method and service needs; which may be targeted in future integrated care interventions, and 2) Important and timely information on a host of psychosocial determinants of family planning, including reproductive autonomy, pregnancy planning/intentions, stigma and social disparities, all of which may uniquely contribute to adverse outcomes among this risk population.

Theoretical Framework:

Social Cognitive Theory guided the creation of the interview guide utilized in the semi-structured interviews. This theory provided a model for understanding the interrelatedness of behavioral, personal and environmental factors and how they influence each other and an individual's decision making. By utilizing reciprocal determinism, the relationship between behavioral, personal and environmental mediates the interconnectedness of each element on the reproductive decisions [11]. The aim was to address these three factors and gain a better understanding as to how they influenced each other and ultimately affected the decisions made regarding a women's reproductive goals and outcomes. An example of personal factors for this population would be how their mental illness influences their cognitive abilities in addition to the other factors. Additionally, an example of environmental factors would be those factors which are external to the individual, such as the physical environment where they live and work in addition to their support systems, such as family and friends. Finally, the behavioral factors are those which are taken by the women, such as her decisions and outcomes, and how they are influenced by these other factors. By addressing all three variables in the interview guide, the goal was to draw conclusions about the individual factors and how they interact and influence each other.

Purpose:

We sought to comprehensively describe the family planning experiences and needs of women with diagnosed SMI seeking outpatient psychiatric treatment in an urban mental health outpatient clinic in order to identify the multi-level barriers to contraceptive use that contribute to unintended pregnancy risk among this group. Via in-depth, semi-structured qualitative interviews, we gained invaluable information about themes such as pregnancy intention, planning, coercion, and reproductive access and barriers. Through these qualitative interviews, we gleaned insight regarding factors that influence autonomy, pregnancy planning, and social factors that affect reproductive choices and decisions among this population. This formative work was designed to inform more effective, holistic models of family planning service delivery and integrated care in order to improve access to contraceptive methods and reduce unintended pregnancies among women with SMI in this vulnerable population.

Chapter 2: Literature Review

The Prevalence and Significance of Serious Mental Illness

Serious mental illness has significant, long-term health and social consequences for reproductive aged women, their families, and society. Severe mental illness (SMI) is a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes or limits one or more major life activities[1]. In 2016, there was an estimated 10.4 million adults living with SMI[1]. Women are more likely to experience higher rates than men [12]. Associated direct and indirect costs for people with SMI exceeded $300 billion a year in 2002, costs which do not account for other associated issues like homelessness and incarceration [13].

There is a general heterogeneity within the umbrella definition of SMI. Clinically, most people with SMI have very different clinical presentations from which their specific clinical diagnosis emerge. SMI encompasses several mental health diagnoses, including major depressive disorder (MDD), post-traumatic stress disorder (PTSD), bipolar disorder, schizophrenia, schizoaffective disorder, and borderline personality disorder[12]. The presentation of these diagnoses can vary and are influenced by age, gender, or sexual orientation. Some patients can present with more florid psychosis as is more often demonstrated with disorders like schizophrenia or schizoaffective disorder, as opposed to other patients who present with more significant mood symptoms, more consistent with a diagnosis like major depressive disorder. Additionally, these disorders are more common than many people realize. Roughly 1.1% of the US population lives with schizophrenia, 2.6% with bipolar disorder, and nearly 6.9% (i.e. 16 million people) had at least one major depressive episode in the last year[14]. Additionally, research has demonstrated that women and men with SMI experience higher rates of comorbidity, medical complications, more frequent emergency room visits, and in general, earlier mortality than the general population by 13-32 years[13]. Women with SMI die on average of 15 years earlier than women who do not have SMI, raising serious questions about the health and ability to access care within this often marginalized population[15].

Changing Models of Health Care Has Implications for Reproductive Health

Accessing health services, especially mental health services, is essential for enabling reproductive-aged women with SMI to lead healthy, happy lives. In the last fifty years, the model of healthcare for this group has changed as fewer individuals remain institutionalized for long periods of time and with a shifting focus to outpatient management of SMI [16]. As previously mentioned the outpatient model of care is now the primary treatment method for people with SMI, focusing on medication compliance, close follow up and a solid patient-provider relationship[2, 17]. This model, which has allowed women with SMI greater patient autonomy and independence, improved interpersonal skills, more socialization, and subsequently new opportunities for engaging in intimate relationships and sexual activity[18], has had important implications for reproductive health.

Family Planning Outcomes Among Women with SMI

There has been a dearth of research on the family planning outcomes of women with SMI. The majority of related work has focused on unintended pregnancy among women with *common* mental health symptoms. For instance, a recent community-based study of nearly 1,000 adolescent and young adult women found the pregnancy risk among those with elevated depression and stress symptoms approached two times that of women without these symptoms[3]. While understudied, it is reasonable to hypothesize that women with SMI experience an even higher risk of unintended pregnancy given reduced cognitive processing, limited decision-making capacity, difficulties with relationship negotiation, and potentially reduced reproductive autonomy[19], all of which may impact their sexual and contraceptive decision-making and behaviors. Although women with psychotic disorders appear to have, on average, the same number of pregnancies as compared to their counterparts without SMI, significantly more of those pregnancies are unplanned or unwanted[5, 20]. One study reported that of the 80 female outpatients at a community mental health clinic with chronic mental illness, 73% had been sexually active within the last year, a third of those did not want to become pregnant despite not using contraception, and 31% had had an abortion[20]. Women with SMI may be more likely to become pregnant unintentionally because of risky and negative sexual experiences, including having multiple sexual partners, sex while intoxicated, and histories of rape and transactional sex, as compared to women without SMI[18]. Poor insight into their mental health disorder and its impact on focus and motivation may contribute to contraceptive nonuse, misuse, or discontinuation[21].

Implications of SMI for Reproductive Health

Moreover, the consequences of unintended pregnancy, including adverse effects on the mental, reproductive, and social wellbeing, can be severe for women with SMI. One small study of pregnancy experiences among 88 psychotic pregnant women and 104 pregnant controls found that over half (59%) of women with schizophrenia reported that their mental health deteriorated in pregnancy[22] . Lack of partner support may also contribute to negative attitudes toward the pregnancy[18]. There is also evidence that stress during the peripartum and postpartum period, accompanied by changes in medication, stress and hormone levels, in conjunction with the physiologic changes occurring in a women’s body, may unmask subclinical disease[23]. These changes may increase the chances of an emerging mental illness but can also result in exacerbating previously existing SMI, such as bipolar disorder, which can have devastating effects on women and their families [23-25]. Additionally, pregnancy complications, such as preterm birth, abnormal placentation, hemorrhages and fetal distress, often related to delayed or inadequate antenatal care utilization[26] are also common in women with SMI. A recent study reviewed the outcomes of pregnant women with SMI in order to determine the prevalence and incidence of both obstetrical and neonatal outcomes. The majority of the women with psychosis had either Medicaid or Medicare, in addition to having higher rates of alcohol/substance abuse, non-psychotic depression, hypertension (both gestational and chronic), and pre-gestational diabetes [25]. Multiple studies have demonstrated that women with SMI and psychosis are at higher risk for placental abruption, hemorrhage, and fetal complications such as distress or congenital abnormalities, [25, 26] which can not only result in a higher incidence of cesarean sections but also increased hospital costs overall [25]. While there is evidence for increased maternal risk for women with SMI in pregnancy, the data is less clear-cut for neonatal outcomes. There is mixed data regarding whether rates of poor fetal growth or intrauterine fetal demise are higher for women with SMI such as psychotic disorders[25-27].

Long-term outcomes may include difficulties parenting and custody loss, which can be devastating to both the parent and the child[2]. Some evidence has suggested the offspring of parents with psychiatric illness are at higher risk for SIDS or sudden infant death syndrome[28]. Additionally, some limited research has shown that the offspring of parents diagnosed with psychiatric illness requiring hospitalization are more vulnerable to death from unnatural causes such as homicide or [29] suicide. Although there is limited research on the long-term outcomes of the offspring of women with SMI, there is a need within this community for a renewed focus on how SMI affects women and their families. Collectively, while the few existing studies and commentaries provide some initial hypotheses and insights into the family planning issues potentially impacting women with SMI, more rigorous studies are needed to better understand the determinants and consequences of unintended pregnancy among this vulnerable population.

Unique Issues Regarding Reproductive Aged Women with SMI

An important piece of the puzzle missing in nearly all of the existing research in women with SMI is how issues such as autonomy, stigma, disparities and how these unique factors are influenced by their mental illness. The majority of the preexisting research on women with SMI is dated and there is little about important issues related to more comprehensive issues such as stigma and autonomy within their families and communities. Recent research has suggested that autonomy is influenced not only by mental health but also cultural factors and norms for some minorities [30]. Another study examined how autonomy and stigma were influenced by mental illness in women with learning disabilities. This study provided insight into how factors such as a strong support system, good coping strategies and resilience allowed these women who often had concomitant intellectual issues and mental health problems to foster a positive outlook on their lives which affected how their approached their limited autonomy and the stigma they experienced about their disability [31]. While these studies don't directly address family planning outcomes, they do provide insight into how stigmatized populations such as minorities and the those with disabilities cope with these issues.

There is also some research about the health effects of stigma on women who have little control in their environments, demonstrating that a lack of autonomy and higher levels of discrimination have an increasingly detrimental effect on health outcomes [32]. Other research suggests that underserved women may benefit from a more patient centered approach to reproductive healthcare counseling in order to address autonomy and disparities which influence their decisions and outcomes [33]. While all of these studies identify how stigma, autonomy and disparities can affect marginalized populations of women, there is limited findings that address women with SMI. Although these studies provide invaluable background into the unique needs and issues of high risk groups of women, there is a definite knowledge gap within the literature in regards to how women with SMI specifically address and cope with experiences involving autonomy, stigma and disparities regarding their reproductive lives.

Research is Needed to Understand and Address Unmet Family Planning Needs for Women with SMI

Addressing the reproductive health needs of women with SMI should be a priority in current health service delivery models. Yet, family planning is not routinely addressed in mental healthcare settings[19, 34], which reflects an important gap given that women with SMI often rely upon psychiatric providers and mental health clinics as their major, and even sole, access point to healthcare. In a study surveying 82 mental health professionals and 80 female patients recruited from five academic medical center-associated mental health clinics, a notable discrepancy in the perceived rate of family planning counseling was found, with providers estimating 25% of their patient population received counseling and only 10% of female patients confirming counseling receipt[34]. Regardless of the discrepancy, the low rate of family planning counseling highlights a likely unmet need in this setting.

Overall, the few existing studies on the reproductive health of women with SMI suggest a potential unmet need for family planning education, counseling, and contraceptive services[17]. Family planning has been given little attention in mental health contexts overall[9], especially for vulnerable populations like those with SMI, which represents a significant gap given that it is a foundation of preventive healthcare required to optimize women’s health, wellbeing, functionality, and reproductive autonomy[17, 18]. Targeted research is needed to provide a more nuanced understanding of the barriers women with SMI may face in accessing and using contraception, especially within current healthcare models in which outpatient mental health clinics are often the initial and only access point for healthcare[18, 34, 35].

Chapter 3. Measures

Study Design and Sample

We conducted qualitative interviews to explore the family planning experiences of women with SMI receiving care at the Grady Outpatient Behavioral Health Center. A qualitative study design allowed us to collect information on an understudied population of reproductive aged women whose family planning needs were potentially not being addressed adequately in the mental health outpatient setting. We recruited women from Grady Outpatient Behavioral Health Center, an outpatient mental health clinic affiliated with Grady Memorial Hospital, which serves the greater Atlanta metro area as well as north Georgia. Grady Memorial Hospital is one of the largest providers of psychiatric care in the state, with its affiliated outpatient clinic seeing approximately 800 patients a month [36]. The Grady Outpatient Behavioral Health Center serves a patient population of women and men with SMI (59% mood disorders; 29% psychotic disorders) whom are mostly uninsured (61%) and of racial/ethnic minority (84% African American).[37] According to visit data from 2015, 168 reproductive aged women with SMI sought care at this clinic during that year, with the majority being African American (82.14%), unemployed and uninsured (61%), and single (82.74%) [38].

Women were recruited via fliers placed in the clinic waiting room and referrals from mental health providers. Diagnostic codes, such as the ones listed below, assisted in identifying women who had a diagnosis of SMI, including major depressive disorder, bipolar disorder, schizophrenia, schizoaffective disorder, and post-traumatic stress disorder (PTSD).[39]

Diagnosis	ICD 10 codes
PTSD	F431
Bipolar disorder	F31

Schizophrenia	F20
Major Depressive Disorder	F329
Schizoaffective Disorder	F25

Inclusion criteria for our study were: 1) female, 2) aged 18-55 years, 3) English speaking, and 4) diagnosis of SMI documented in their medical record at the Grady Outpatient Behavioral Health Center. Our main exclusion criteria was any signs or symptoms of active suicidal ideation, which was assessed upon completion of the study consent (via the Suicide Behaviors Questionnaire-Revised or SBQ-R[40]) or as determined by their mental health provider. Potential participants whose cumulative score was greater than or equal to 8[40] were evaluated by a clinician at the Grady Behavioral Health Clinic shortly after completing the assessment. The clinician conducted their own evaluation of the participant to determine if they are actively suicidal or if their suicidality is a chronic condition, as it is for many people with SMI.

As we learned early into recruitment, chronic suicidality is can be a common issue for people with SMI with the aforementioned diagnoses. Chronic suicidality is defined as clinically persistent or repetitive intermittent passive or active suicidal thoughts, planning and/ or occasional intercurrent suicide attempts[41], generally associated with various psychotic disorders, traumas and an array of other psychiatric issues. A clinician's assessment included a suicide risk assessment and plan of care to ensure each subject had an action plan to get help if they became actively suicidal. None of our participants were deemed actively suicidal but several were determined to be chronically suicidal. When participant's score was >8 on the SBQ-R scale, they were evaluated closely by a clinician immediately[42]. These potential participants were screened thoroughly and during our study period, all were determined to be chronically suicidal. After an appropriate safety plan was put into place by the clinician and participant, the clinician and the interviewer (ML) would discuss if the participant was stable enough to participate in the study. Appropriate and timely follow up was arranged for all women, regardless of a diagnosis of chronic suicidality. Additionally, we offered on site psychiatric assistance for all chronically suicidal participants at the time of the interview.

Measures

The in-depth, individual interviews were conducted entirely at the Grady Outpatient Behavioral Health Center and ranged in length from thirty to ninety minutes, depending on participant. Each interview was facilitated by a semi-structured interview guide, which we developed with key constructs of the Social Cognitive Theory in mind to measure key individual-, social/institutional, environment- and behavioral-level factors (see Appendix A). We also drew upon prior relevant quantitative work, including Upadyhah's Reproductive Autonomy Scale, a survey of multi-level barriers to contraceptive method and family planning service use, and Hall's sexual and reproductive health stigma scale employed in prior research [43-45]. The guide was written to explore themes such as: 1) women's experiences with and perceptions of reproductive health and family planning services and contraceptive methods, within mental health care, reproductive health care, and other care settings (behavioral), 2) any perceived logistical and social barriers that may be operating at multiple levels (family, health systems, community, macrosocial factors) to preclude contraception and family planning service use (social environment), 3) perceived unmet contraceptive and family planning needs (individual), 4) perceived reproductive autonomy and interpersonal experiences with family planning decision-making and communication with health providers, partners, parents, others (individual and social environment), 5) pregnancy intentions and pregnancy planning (past and current) (individual), and 6) the potential role of stigma (e.g. mental, reproductive, interactive) in shaping their health and healthcare experiences (social environment).

We relied on Social Cognitive Theory for a theoretical framework for the interview guide, as it proposes that the reproductive lives of the women within this population are likely influenced by their actions, cognitions, and environment through a process called 'reciprocal determinism.' Bandura surmised that each factor mediates the other in an interconnectedness which allows for fluidity and influence of, for example, individual and behavioral determinants to effect one's environment[11]. The range of questions in our interview guide allowed assessment of how the environmental and the social factors select and create certain behaviors which are mediated over time as their social and environmental surroundings change and are effected by their mental illness.

Procedure

After potential participants expressed interest in the study, they were given initial information about the study and the likely time commitment required by participation. They also gave permission to have study staff review their records to ensure they met inclusion criteria (specifically a documented diagnosis of SMI). Once inclusion criteria were confirmed, they received a phone call where the details of the study, including the study question, time commitment, compensation and the general subject matter of the qualitative guide, were addressed in greater detail. After all questions were answered, arrangements were made for follow up in order to complete the study. Three attempts were made to contact each potential participant if they did not respond to the initial follow up phone call giving specifics regarding the study.

Participants reviewed and signed a written consent (Appendix A) at the time of the scheduled interview. The participants were offered a signed copy of this consent and another copy was kept in study records. Semi-structured in-depth in-person interviews were conducted to explore the reproductive health and family planning experiences, perceptions, and needs for care of women undergoing outpatient treatment for SMI. Interviews lasted anywhere from thirty to ninety minutes, and explored a range of topics, moving from less sensitive to more in depth and complex as a rapport was created in the majority of interviews. We explored topics such as obstetrical and gynecological histories, any sexual partners they wanted to discuss, any history of sexual abuse or trauma in addition to reviewing in details regarding a myriad of reproductive issues, such as pregnancy intention and planning. Interviews were recorded and transcribed verbatim and entered into MAXQDA software. The transcripts were reviewed, cleaned, and any identifying data was removed from the transcript. As is appropriate for any qualitative study, our final sample size was determined by data saturation (i.e. the point at which no new information emerges) at 17 women.

Analysis

A code book was created, relying on an iterative process allowing for the code book to be refined throughout the coding process. The research group met every other week to review findings and decide on codes and memos that were put forth by the initial coders to refine the codebook. These meetings allowed the research teams to discuss emerging codes and subcodes and to resolve any discrepancies between codes [46]. Initially, each interview was coded and analyzed by two researchers (ML and SC) independently in order to verify codes and ensure optimal analysis of the transcribed interviews. After more than half of the interviews were coded and verified against each other to ensure consistent coding and interrater reliability, the remaining interviews were coded independently by one of the coders (either ML or SC).

Our approach to qualitative coding was based on grounded theory, utilizing inductive and deductive codes. Grounded theory is defined as a methodology where theory is created by systematically analyzing data for emerging ideas repeated in interviews [47]. During the initial interviews, recurring themes emerged early on which evolved throughout the interview and coding process. Additionally, other themes emerged while coding the transcripts, informed by previously created codes and memos. Other themes were gleaned from the literature search on the existing literature and modified from initial analysis. Examples of themes were pregnancy intention and planning, stigma, access and autonomy issues related to family planning and SMI[46, 47]. All transcripts and files were stored in secure, password protected or locked offices.

Chapter 4. Results

To our knowledge, this is among the first qualitative studies examining the reproductive experiences of women with SMI. The majority of the women we interviewed were eager to share their experiences, and numerous women mentioned that they had never shared these stories before either with their friends, families or their mental health providers. Many women spoke about how difficult it was to share their histories about difficult obstetrical deliveries or sexual or physical assaults, but how essential it was for their healing process. Most women were eager to discuss these stories and several mentioned that sharing was important to them, especially if it was a part of research which could help other women with SMI.

We interviewed 17 women with SMI, recruited from the Grady Outpatient Behavioral Health Clinic. Table 1 demonstrates their demographic characteristics, including age, race, relationship status, disorder, lifetime contraceptive methods used and reproductive history. Table 2 lists the major themes that emerged from the qualitative data. The majority of the themes address pregnancy: pregnancy intention, pregnancy decision making and coercion. These themes emerged from the data and provide invaluable information about how the women who participated in the study addressed their unintended pregnancies, what affected their decisions and who or what influenced their decisions to continue or terminate an unintended pregnancy. The remaining two themes address what affected their ability to access care and what influenced their care. The women who participated in this project were recruited from an outpatient mental health clinic and therefore were already accessing healthcare. However, several themes emerged from their discussions about the issues accessing reproductive healthcare, including specific and unique barriers.

Table 1: Demographic Characteristics

N=17	**Categories**	**Number or participants**	**Proportions**
Age	18-25	1	6%
	26-35	6	35%
	36-45	5	29%
	46-55	6	35%
Race	Black/ African American	9	53%
	White	4	24%
	Biracial	1	6%
	Other	3	18%
Relationship	Not in a relationship	9	53%
	Divorced or separated	4	24%
	Married	2	12%
	Engaged	1	6%
	Living with long term partner	1	6%
Disorder	Bipolar disorder	3	18%
	Bipolar disorder w/ psychotic features	4	24%
	Major depressive disorder (MDD)	6	35%
	MDD with psychotic features	2	12%
	Post traumatic stress disorder	6	35%
	Schizoaffective disorder	2	12%
	Psychosis NOS	1	6%
Method	Condoms	16	94%
	Oral contraceptive pills	15	88%
	Withdrawal	8	47%
	Depo Provera	7	41%

	Implant	3	18%
	Patch	2	12%
	Tubal ligation	2	12%
	Norplant	2	12%
	Female condom	2	12%
	Foam	1	6%
	Spermicide	1	6%
	IUD	1	6%
		Mean	**Standard Deviation**
Reproductive History	Number of pregnancies	2.94	2.28
	Number of live births	1.76	1.82
	Number of miscarriages	0.44	0.63
	Number of abortions (medical or surgical)	0.81	1.17

Table 2: Themes

	Themes
1	Pregnancy Intention
2	Pregnancy Decision Making
3	Pregnancy Coercion
4	Access to Reproductive Care
5	Barriers to Reproductive Care

I. Unintended pregnancy

Unintended pregnancy was a common theme that emerged from participant interviews. First pregnancies and rapid repeat pregnancies during adolescence were commonly reported among this sample. Numerous women reported first pregnancies at age 14 and many of those pregnant at 14 had rapid repeat pregnancies prior to age 19. Nearly all of the women who had been pregnant admitted to at least one (if not more) unintended pregnancy. The general feelings toward any pregnancy planning, preparing for pregnancy or prevention of pregnancy were often met with ambiguity. Several codes such as autonomy of pregnancy, pregnancy intention, contraceptive compliance and high risk sexual behavior demonstrated how 'pregnancy intention' emerged as a theme within these interviews. There were several topics that emerged in the interviews when women were asked about pregnancy intention. The aforementioned codes illustrated how pregnancy intention was often influenced by factors such as general ambivalence, pregnancy prevention not being a priority or poor contraceptive compliance. As one women said:

> *"I was just having sex and if I got pregnant I did, and if I didn't, I didn't. It was in God's hands."*

Many women felt that pregnancy was a chance they took by being sexually active with someone. Other women expressed that while they weren't necessarily planning for pregnancy, they also were not opposed to the ramifications of sex, especially if they had intense feelings about a romantic partner as one woman stated:

> *"But as time went on, me and him got active. But I was crazy about him. I mean, I want to be with this man. [Laughs] I want him to be my husband. I didn't care about getting the shot. If I get pregnant, I get pregnant. That's just how I felt."*

This quote demonstrates how contraception was not always a priority with women and therefore many women knew an unintended pregnancy was a possibility. When asked about pregnancy planning, many women discussed how compliance with contraception could be difficult, especially when it came to user dependent methods, such as birth control pills. As one women said:

> *"The first (pregnancy) wasn't planned. The second one, I was taking birth control pills, but I was like, forgetting…"*

Remembering to take the pill daily was difficult for many women and numerous women reported poor compliance on oral contraception, resulting in pregnancy, as demonstrated by this woman who said:

> *"I just personally think I wasn't taking (the pills) every day like I was supposed to. That's probably the reason why I came up pregnant."*

The factors that emerged under the theme of unintended pregnancy, whether it was contraceptive misuse, pregnancy prevention not being a priority or intimate relationships competing with pregnancy prevention, general pregnancy ambiguity and lack of pregnancy intention, or lack of perceived reproductive autonomy, were closely related to one another but also shaped another theme uncovered in participant's stories - pregnancy decision making.

II. Pregnancy Decision Making

These women also discussed the context of and ways in which they made decisions regarding the outcome of their unintended pregnancies. Various codes that addressed pregnancy intention, decision making and partner influences culminated to produce this finding. The decision regarding the outcomes of these unintended pregnancies was often influenced by the woman's relationship with the partner. In scenarios where there was little or no relationship with the partner or that the partner was not seen as someone who may help provide for the pregnancy and the participant, many women made the choice to terminate that pregnancy. As one participant stated:

"So he had all these different women with children. And I knew that he had this all going on because he told me. And I ended up becoming pregnant, and I was not gonna be another of those women, so I went and just had the abortion and I told him later on…."

This quote illustrates what an important role the women's quality of her relationship with the intimate partner was in addition to how he supported his other children. This participant felt strongly about how this partner would not be able to support neither her nor another child, which lead to her having a termination. Many women echoed similar sentiments similar thus demonstrating how a lack of 'partner support' could affect a pregnancy outcome. For many women, the decision to terminate was a more immediate reaction to discovering they were pregnant in a situation where there was a poor relationship or no relationship and therefore limited or no support. This was demonstrated by one woman who stated:

"I got an abortion. Things weren't right, things weren't good, and I didn't want his baby either…"

This quote further expresses how limited support and lack of a quality relationship with the male partner affected the outcome of unintended pregnancies for women. Conversely, these same aforementioned codes also demonstrated how a good relationship with a partner could influence the outcome of an unintended pregnancy. When there was a positive relationship with the partner, the news of an unplanned pregnancy was oftentimes met with enthusiasm, as one participant stated:

"I wanted the baby, 'cause I liked the man at the time. I wanted to be with the man, so I kept the baby. I don't even know if I really wanted the baby, but I don't know."

The overall optimistic feelings toward the partner seemed to influence her attitude toward the pregnancy and sometimes even overshadow her own uncertainty. Women described scenarios where they felt they could talk to their partners about their unintended pregnancies and this support provided hope and stability for their choice to continue with the unintended pregnancy.

> *"And I told him, then we just talked about the pregnancy. We planned it and we got married…it was a lot of mixed emotions. He was in the military, so we decided to keep the baby at that point."*

As this quote suggests, a positive relationship with a partner allowed women to feel supported by their partners and to make plans not only for the unplanned pregnancy but also their lives. This support, ranging from financial to emotional, often times resulted in the decision to maintain unintended pregnancies, suggesting the importance of a supportive partner for these women with SMI.

III. Coercion

Another prominent theme that emerged from the interviews was how partners or family members often pushed their own views upon these women when it came to the outcome of their unintended pregnancies. The theme emerged from codes such as autonomy, coercion, self-esteem coupled with topics how the influence of family and partners on decisions regarding abortion.

A. Influence of partners:

Several participants echoed this feeling of making the decision to terminate a pregnancy based on their partner's influence, whether it's their partner's opinion or how the pregnancy may affect their relationship. Oftentimes, if the woman had a relationship with the partner and the partner expressed feelings toward the pregnancy, many women deferred to the partner regarding the outcome of the pregnancy. In several situations, these women felt coerced into continuing or terminating a pregnancy based on partner preference. As one participant said:

> *"And since he was the one complaining about the cervical cap, and knew that that was the only form of birth control that I was using, he should've know flat out I was gonna get pregnant. And when I came up, it was no surprise that I was pregnant… For him to turn around after finding out that I'm pregnant, and say, 'No, we're gonna have an abortion,' was kind of a slap in the face. It was just really wrong."*

This participant expressed a lot of regret during her interview about this situation as she felt pushed into terminating a pregnancy. She felt strongly that not only was she coerced into removing her cervical cap which was her primary contraceptive method but also pressured into ending the subsequent pregnancy.

B. Influence of family

Other women talked about the influence of their parent's input regarding their unintended pregnancies and how that affected the outcome of their unintended pregnancy. This was especially evident when the unintended pregnancies occurred while the participant was a minor as demonstrated by the following quote:

> "I felt like I was too young to have a baby. I wanted to get rid of the baby, but my mama said, 'No.' She said, 'You laid down to have that baby. You gonna keep this baby. I don't believe in abortion and you not having no abortion.' "

Parental pressure was more common in earlier pregnancies, specifically if the woman was a minor. For many women, they're first pregnancies occurred with they were in high school and still living at home. Parental coercion was subtler for some women who spoke about how their mothers influenced their decisions about unintended pregnancy. One woman spoke about how she was not sure about her decision to keep her pregnancy until the delivery of her son and said:

> *"He was just a handsome little bundle of joy. And I just started crying. But I was crying 'cause I just think that I wanted to take a life that didn't ask to come into this world. And that's what my mama kept putting in my head. She was like, 'God wouldn't be pleased if you take a life.' So, that's why I didn't."*

As this quote demonstrates, continued pressure often played powerful roles in the decision making process for unintended pregnancies. Some women also spoke about how their mother's initially tried to stay neutral but over the course of the decision making process, would voice their own opinions frequently which was another form of pressure or coercion. One woman said:

> *"My mom was telling me, 'You need to go ahead and make that decision. You can't take care of yourself right now, let alone a baby.' And at the time, she liked the new boyfriend. And she, was just saying, 'Well, how does that look?' But we're talking about a life. But if neither guys were there, how can I take care of this baby?"*

Parental pressure took various forms whether it was termination or maintaining a pregnancy. Ultimately, many women acknowledged how this pressure played pivotal roles in their decisions regardless of the outcome. Whether the source was a partner or a parent, coercion was a theme that emerged repeatedly as woman talked about how they made these decisions and what influences were most prominent. Women did not always recognize this pressure as coercion at the time of the decision but often remarked during our interviews that this pressure integral in how they made a decision about their unintended pregnancies. After making these difficult decisions, many women often accessed the healthcare system for the first time which was also a theme that emerged during our interviews.

IV. <u>Accessing Reproductive Healthcare</u>

Nearly all of these women had received either education or services regarding either pregnancy or contraception at subsidized teen or family planning clinics such those affiliated with hospitals or a Planned Parenthood location. Many women also spoke about utilizing services such a pregnancy Medicaid, "welfare", DFACS and social workers. Several topics were reiterated throughout the interviews, such as abortion experiences, establishing prenatal care and accessing care demonstrated how prevalent this was during the interviews.

A. Inability to Access Care

Many women were not seeking regular, routine reproductive healthcare either due to inability to access care or lack of knowledge regarding where to go for care. An inability to access to reproductive healthcare was mentioned as many women spoke of the difficulty to access healthcare or user dependent contraceptive methods, such as birth control pills. As one woman said:

> *"You should automatically (get) a certain level of birth control you know? Because now, with me not being able to go back and see on OBGYN for nearly two years, I could have two babies."*

Despite their regular follow up with their mental health providers, most women were not seeking regular reproductive health care. Therefore, it is clear that they are accessing the healthcare system regularly but there is an unmet need for reproductive healthcare that is being missed within this population.

V. Barriers to Reproductive Healthcare

There were several unique barriers to women with SMI in attempting to obtain reproductive healthcare. As mentioned, these women were receiving mental health services but many were not receiving annual family planning or gynecological care. This begged the question as to the role of mental health providers in the provision of reproductive services for this at risk group of women.

A. Role of Mental Health Providers

Additionally, although many women said they would feel comfortable talking about reproductive health or contraception with their psychiatric providers, most women did not discuss this with their psychiatric providers. Not only did most women deny discussing contraception with their mental health providers, but few mentioned discussing pregnancy planning with their providers. Many women stated that they felt comfortable with their mental health providers however only one participant remembered a direct interaction with their psychiatrist where she discussed planning for pregnancy. She was trying to get pregnant and asked her psychiatrist and recalled:

> *"…She just said that I would have to have – my levels would – had to have been a certain level in order to be healthy for a fetus, and so she put me on a certain vitamin and told me to talk to my primary care physician, which I didn't get a chance to talk to my primary care physician about that. I don't believe I did. I just took the herbs for a while, and then I just – I think I missed my periods for a while. And so I thought I went into menopause, and thought, 'Well, no chance now.'"*

This quote demonstrates her psychiatrist's willingness to assist her in preparing for pregnancy although the participant is unclear regarding what those exact precautions were to optimize her for pregnancy. The other participants stated their reproductive care was generally through teen or family planning clinics where their follow up was generally less regular than their psychiatric follow up. The paucity of reproductive healthcare amongst this population who was seeking regular psychiatric follow up was an important theme, which demonstrated a critical gap in healthcare for this high risk population of women.

B. Barriers to Addressing Reproductive Care with Mental Health Providers

A theme emerged from codes addressing the relationship with the psychiatric provider, discussing contraception and pregnancy, demonstrating how reproductive healthcare was not discussed in the psychiatric setting despite their higher rates of high risk sexual activity and unintended pregnancy. When asked about discussing sexual behavior with their mental health providers, many women seemed open to this but reiterated that they were never asked about reproductive healthcare. As one woman said:

> *"They just ask me do I have anything on my mind and stuff like that. Or they ask me how are the medication, how's I'm doing on my meds and stuff. Or do I need to go up or do I need to*

go down, stuff like that. But we never talk about birth control, nothing like that."

The participant suggests the interactions with mental health providers are varied and that sessions may address immediate needs, such as medication compliance and refills. However, if the patient does not address her issues or concerns about contraception, it could be assumed that these needs may get missed or over looked for more urgent issues.

As numerous women discussed their inability to access health care due to financial constraints or lack of knowing where they could receive services, in addition to dealing with their chronic medical conditions, a clear health care gap emerged within this population. This gap was more evident in that these women were accessing mental health services in a healthcare setting with a Title X-funded family planning clinic, but few participants or providers were aware of these services. This suggests that accessing reproductive health care has local solutions available, such as improved education of providers and a more efficient referral network which could significantly improve health outcomes for these women.

Chapter 5. Discussion

Findings

The themes that emerged from our data address not only unintended pregnancy but also the issues that surround it: how women make decisions about unintended pregnancy, what or who influences those decisions, and how coercion plays a role amongst this population. The influence of parents and partners upon decisions regarding unintended pregnancy was consistently reported by these women, with parental influence more obvious in the earlier years and the partners having more control as women became older. Previous research suggests that overt pregnancy coercion or contraception interference are more common ways that partners influence women at risk for unintended pregnancy, although this research has mostly focused on general samples of women and not included women with SMI [48-50]. Our data supports these findings as various partners interfered with choosing a method of contraception or pressured women to continue or terminate their pregnancies. However, our findings also suggest that this relationship may be more nuanced. Many of our participants often described the quality of the relationship with their partner, in addition to gauging the partner's potential for financial and emotional support, when discussing their decision about the outcome of an unintended pregnancy. Decisions about an unintended pregnancy were steeped in concern over how their partner could help support them, in addition to how this pregnancy would affect their own lives. These interviews exhibited how the health of a relationship and the presumed level of support from a partner affect the complex decision-making process involved with unintended pregnancies. Many women with SMI cope with how their mental illness affects their social support and their financial responsibilities[35]. Some women are alienated by their diagnosis or have a hard time maintaining employment [35] and an unintended pregnancy dramatically impacts these issues as well as their relationships with partners and families.

Another important theme that materialized from our data was how our participants accessed care and what barriers they experienced in accessing or using reproductive health services. Our participants were all recruited from an outpatient behavioral health clinic, and therefore had already gained access into the one of the largest safety net health care systems in the state. While many women saw an Obstetrician/Gynecologist during the course of their reproductive lives, most women were not routinely seeing someone about their reproductive health. Previous literature has demonstrated how financial constraints limit women with SMI from accessing healthcare as many women are either on government assistance or are uninsured and are unable to afford even the lowest copayments [35]. Additionally, fear of major medical issues can often delay women with SMI from attempting to access care[35]. Among our participants, many women were unsure about how to access reproductive care and did not discuss these issues with their providers.

In addition to women not knowing where to go for reproductive healthcare, many women also did not recall being asked about their reproductive health on a routine basis by their psychiatric providers. These findings demonstrate a gap in their health care needs, particularly given that most women were sexually active (and at early ages and with multiple partners commonly) and employing methods of contraception that were highly user-dependent or partner-dependent, thus placing them at a high risk for unintended pregnancy. Several other studies have demonstrated the importance of communication between primary care physicians and mental health providers regarding women with mental illness[35, 51]. Collaboration between providers may not only expedite care but also improve care for these women at higher risk for poor mental and physical health problems[13, 35, 51].

These findings demonstrate a gap in reproductive health follow up and a dearth in dialogue regarding the affects medication may have upon sexual health and pregnancy. This suggests why collaborative efforts such as an efficient referral network between psychiatric providers and reproductive health providers is imperative for women with SMI. Additionally, our findings indicate that more research is needed in investigating how psychiatric providers may or may not address contraception and reproductive health among an at risk populations. This underscores the importance of collaboration between mental and reproductive health providers in order to prevent reproductive aged women with SMI from falling through the gaps in care.

Public Health Implications:

Via the use of Social Cognitive Theory (SCT) in our study, we sought to further define how personal, behavioral, and environmental factors influenced the health decisions and outcomes of our participants with SMI. Our results demonstrate how connected these factors are, suggesting that when one of these factors changes, the others are affected and therefore decisions and outcomes are swayed. We applied the theoretical construct of reprocial determinism, often utilized in SCT, to our results to determine how behavioral factors (mental health) and environmental factors (influence of family and friends) affect personal circumstances (decisions regarding reproductive health)[11]. Our qualitative results suggest that behavioral and environmental components strongly affect individual influences. Most participants relayed how the external social influences of their family and friends (environmental) heavily affected their mental health (behavioral), ultimately shaping decisions about their reproductive health (personal). This triad was apparent during the complex decision making around unintended pregnancies. Many participants spoke about how the opinions from family and friends affected their mental health as they struggled to make very personal, individualized decisions regarding the outcome of an unintended pregnancy. Future qualitative research would benefit from application of this model to this population, further demonstrating the intersectionality of these concepts.

Our findings point to several implications for public health research and practice. There is a growing reproductive health crisis amongst women in the US and Georgia has one of the highest rates of maternal mortality in the country[52]. While morbidity and mortality estimates do not often reflect women with SMI specifically, there have been some reports suggesting that women with SMI are indeed at higher risk for worse maternal and obstetrical outcomes [26, 53]. Our qualitative findings in this study suggest that these vulnerable women experienced multi-level factors contributing to their unintended pregnancy and reproductive health experiences. They lacked reproductive knowledge, access to care, and social support which appeared to contribute to negative outcomes. This suggests that accessing reproductive health care has local solutions available, such as improved education of providers and a more efficient referral network which could significantly improve public health outcomes in this setting.

Future research investigating how psychiatric providers address reproductive health, in particular exploring how reproductive coercion is recognized and addressed, amongst at risk populations is essential in continuing our understanding of the reproductive needs of women with SMI. Further research on the contraceptive choices and impact of unintended pregnancies upon women with SMI would provide further insight into these complex decisions. And yet in many respects, reproductive health needs for women with SMI are similar to those of other at-risk groups. Previous research on women in lower socioeconomic settings, who are also at risk for unintended pregnancy, but have not been diagnosed with SMI have suggested that feelings of pregnancy ambiguity, how relationships affect pregnancy decision making, and the causes of coercion are also important themes. Given the overlap in reproductive needs amongst women with SMI and at-risk women without SMI, interventions may be informed by proven successful strategies in other settings. Furthermore, both populations would likely benefit from subsequent research in these areas.

Strengths and Limitations:

An important strength of this novel research is that it focused on an understudied population of women with high risk sexual behavior, who were at risk for unintended pregnancy. Also, because we were able to interview women aged 20-55 years old, we were able to garner a wealth of experience from women at various age points. Additionally, our location provided an impressive array of mental health diagnosis which also enhanced our findings for women with SMI.

Our study also had several limitations. A limitation in this study is that we interviewed women who were able to successful access outpatient mental health care. Another limitation is the concern for bias in our results. Despite using semi-structured interview guides, there is always a risk of interviewer bias as the interviewer could influence the data collection and analysis. Additionally, there can be a risk for recall bias given that several women were recalling details about an experience that was more than 20 years. Also, our sample is also not a representative sample of women with SMI and therefore our results are not generalizable.

Conclusions:

This study highlighted the unique reproductive health experiences of women with SMI who are in outpatient mental health treatment at a large safety net hospital. Several key themes emerged from the reproductive health histories, detailing how decision making, relationships with partners, and coercion from family and friends influence decisions regarding unintended pregnancies. Additionally, these women shared their experiences with reproductive healthcare, including barriers and unique circumstances that surround their ability to access these services. The themes which emerged from our qualitative research suggest that there is a nuanced decision making process involved in determining the outcome of unintended pregnancies in addition to demonstrating the complex issues in accessing reproductive healthcare for women with SMI. Our findings demonstrate how social and environmental factors influence individual behaviors as these women make reproductive decisions and seek family planning care, influenced by their mental illness. Additionally, this study not only illustrates the importance of further research in the reproductive experiences and outcomes of this group but also solidifies the urgency in providing access to reproductive health care in this at risk population.

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Appendix A

You Are Being Asked to Be in a Research Study

What Is a Research Study?
The main purpose of research studies is to gain knowledge. This knowledge may be used to help others. Research studies are not intended to benefit you directly, though some might.

Do I Have to Do This?
No. Being in this study is entirely your choice. If you decide to join this study, you can change your mind later on and withdraw from the research study.

Taking part in a study is separate from medical care. The decision to join or not join the research study will not affect your status as a patient.

What Is This Document?
This form is an informed consent document. It will describe the study risks, procedures, and any costs to you.

This form is also a HIPAA Authorization document. It will describe how your health information will be used and by whom.

Signing this form indicates you are willing to take part in the study and allow your health information to be used. You may also be asked to participate in future studies.

What Should I Do Next?
1. Read this form, or have it read to you.
2. Make sure the study doctor or study staff explains the study to you.
3. Ask questions (e.g., time commitment, unfamiliar words, specific procedures, etc.)
4. If there will be medical treatment, know which parts are research and which are standard care.
5. Take time to consider this, and talk about it with your family and friends.

Emory University and Grady Health System
Consent to be a Research Subject / HIPAA Authorization

Title: Barriers to family planning among women with severe mental illness

Principal Investigator: Kelli Stidham Hall, MS, PhD

Study-Supporter: Society for Family Planning Research Fund

Introduction

You are being asked to be in a medical research study. This form is designed to tell you everything you need to think about before you decide if you want to be a part of the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.** The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Before making your decision:

- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. You may wish to discuss your decision with family or friends. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. By signing this form you will not give up any legal rights.

What is the purpose of this study?

The purpose of this study is to understand the family planning experiences and contraceptive needs of women with severe mental illness (defined as Major depressive disorder, bipolar disorder, schizophrenia, schizoaffective disorder, and PTSD) who are receiving mental health care at the Grady Behavioral Outpatient Mental Health clinic. We are also interested in exploring the barriers that women with severe mental illness face in accessing family planning services and birth control methods.

What will I be asked to do? If you agree to be in the study, we'll complete a short survey so that we can learn a little more about you. A researcher will ask you the questions out loud. Then, the researcher will interview you about your experiences with birth control and family planning services at the Grady Behavioral Outpatient Mental Health clinic. The interview will take about an hour. We will record the interview. After the interview, we will write down your answers, and at that time, take out any names or other information that could identify your or others and then we will destroy the recording.

Who owns my study information?

If you join this study, you will be donating your study information. If you withdraw from the study, your data will be removed from our files and destroyed.

What are the possible risks and discomforts?

There may be side effects from the procedures that are not known at this time. During the interview, you may experience some discomfort if thinking about unpleasant experiences or prior situations related to the questions that we ask you.

It is possible that the researchers will learn something new during the study about the risks of being in it. If this happens, they will tell you about it. Then you can decide if you want to continue to be in this study or not. You may be asked to sign a new consent form that includes the new information if you decide to stay in the study.

Will I benefit directly from the study?

This study is not designed to benefit you directly. Your mental health may improve while you are in this study but it may not, and it may even get worse. This study is designed to learn more about your experiences with getting family planning care. The study results may be used to help others in the future.

Will I be compensated for my time and effort?

You will be offered refreshments during the study as well as a MARTA card or a parking pass to cover transportation costs. You will also receive a $50 Visa gift card for your participation in the study.

What are my other options?

If you decide not to enter this study, your care and treatment at the Grady Outpatient Behavioral Health Center will not be affected.

How will you protect my private information that you collect in this study?

Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents.

Storing and Sharing your Information

Your health information will be stored and potentially shared with other researchers. The information will be available for any research question, such as research to understand more about women with mental health problems and accessing healthcare.

Costs

There are no costs, research or standard of care related, associated with the study.
There will be no costs to you for participating in this study, other than basic expenses like transportation for which you will be reimbursed. You will not be charged for any of the research activities.

Withdrawal from the Study

You have the right to leave a study at any time without penalty.

The researchers also have the right to stop your participation in this study without your consent for any reason, especially if they believe it is in your best interest or if you were to object to any future changes that may be made in the study plan.

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act and regulations (HIPAA). We refer to all of these laws as the "Privacy Rules." Here we let you know how we will use and disclose your PHI for the study and for any optional studies in which you may choose to participate.

PHI that Will be Used/Disclosed:
The PHI that we will use or share for the main research study includes:

- Medical information about you including your medical history and present/past medications.

Purposes for Which Your PHI Will be Used/Disclosed:
We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment and for payment for such treatment. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information

Use and Disclosure of Your Information That is Required by Law:
We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults. We will also comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Authorization to Use PHI is Required to Participate:
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study.

People Who will Use/Disclose Your PHI:
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigator and the research staff will use and disclose your PHI to conduct the study
- Emory and Grady Health System may use and disclose your PHI to run normal business operations. c

- The Principal Investigator and research staff will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- The Society for Family Planning is the Sponsor of the study. The Sponsor may use and disclose your PHI to make sure the research is done correctly and to collect and analyze the results of the research. The Sponsor may disclose your PHI to other people and groups like study monitors to help conduct the study or to provide oversight for the study.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
    - Emory and Grady Health System offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRBs, the Grady Research Oversight Committee, the Emory Research and Compliance Offices, and the Emory Office for Clinical Research.
    - Public health agencies.
    - Research monitors and reviewer.
    - Accreditation agencies.
- Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your PHI may be shared with that new institution and their oversight offices. PHI will be shared securely and under a legal agreement to ensure it continues to be used under the terms of this consent and HIPAA authorization.

Expiration of Your Authorization

Your PHI will be used until this research study ends.

Revoking Your Authorization

If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at: (678) 829-2053 or by emailing FPstudy2017@gmail.com.

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy

Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information won’t be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study. **Contact Information**

Contact Dr. Lawley at (678) 829-2053 or FPstudy2017@gmail.com:

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

If you are a patient receiving care from the Grady Health System and have a question about your rights, you may contact the Office of Research Administration at research@gmh.edu.

Consent and Authorization

TO BE FILLED OUT BY SUBJECT ONLY

Please **print** your name, **sign**, and **date** below if you agree to be in the main study. By signing this consent and authorization form, you will not give up any of your legal rights. We will give you a copy of the form to keep.

____

Name of Subject

____ ______________

Signature of Subject (18 or older and able to consent) **Date**

TO BE FILLED OUT BY STUDY TEAM ONLY

____

Name of Person Conducting Informed Consent Discussion

____ ______________

Signature of Person Conducting Informed Consent Discussion **Date** **Time**

Appendix B: Participant Interview Guide

Participant interview guide

Survey ID:
Date:
Start time:
End time:

Hi! My name is Megan Lawley, I am an Obstetrician Gynecologist and a fellow in Family Planning. I am interviewing participants from the clinic for a research study. My research is focused on your attitudes and experiences seeking family planning care. I am going to ask you some questions today, some of which are personal, about topics that can be hard to talk about, and I really appreciate you taking the time to answer these questions. You can stop the interview at any time, as your participation is voluntary. Also, what we discuss today is confidential in that your answers will only be used for our study purposes and no one will ever know these are your specific answers.

I would like to start by asking you some brief questions that I will complete on a tablet for you.

1. Name:
2. DOB:
3. How do you usually describe yourself?
    a. White
    b. Black or African American
    c. Hispanic or Latino
    d. Asian or Pacific Islander
    e. American Indian, Alaskan Native or Native Hawaiian
    f. Biracial or multiracial
    g. Other: please specify
4. What is your current marital or relationship status?
    a. Married
    b. Engaged
    c. Living with your romantic partner (cohabitating)
    d. Divorced or separated
    e. Long-term romantic relationship but not married, engaged or cohabitating
    f. Casual relationship that involved physical or emotional contact
    g. Not in a relationship
5. How long have you been receiving care at this clinic:
6. What mental health illnesses have you been diagnosed with:
    a. Major Depressive Disorder
    b. Bipolar Disorder
    c. Schizophrenia
    d. Schizoaffective Disorder
    e. PTSD
    f. Other
7. What medications do you take:
8. Have you ever used birth control before:

  - a. Yes
  - b. No
  - c. Not sure

9. Who prescribed you birth control:
  - a. OBGYN
  - b. Psychiatrist
  - c. Primary care doctor
  - d. I’m not sure/ I don’t remember
  - e. I have never been on birth control

10. What types of birth control have you used before:
  - a. Intrauterine device (IUD; for example, Mirena, Paragard or Skyla)
  - b. Implant (for example, Implanon or Nexplanon)
  - c. Pills (for example, Ortho Tri-Cyclen or Yaz)
  - d. Patch (for example, Ortho Evra)
  - e. Ring (for example, Nuvaring)
  - f. Injectable (for example, Depo-Provera shot)
  - g. Condoms
  - h. Withdrawal (“pulling out”)
  - i. Emergency contraception (“morning after pill”)
  - j. Other barrier methods (for example, diaphragm, sponge, cervical cap)
  - k. Other contraceptive method (please specify):
  - l. I have never used contraception before

11. How many times have you been pregnant:
12. How many children have you delivered:
13. How many miscarriages have you had:
14. How many abortions have you had (either medical or surgical):

Thanks for going through those questions with me. We’re now going to talk more in-depth about some of your reproductive health and family planning experiences.

Primary Objectives
I. Women’s experiences with, perceptions of, and perceived unmet needs for reproductive health and family planning services and contraceptive methods (in mental health care, reproductive health care and other care settings)

This conversation will focus on your experiences seeking family planning services and birth control, as well as potential unmet needs you may have for family planning and birth control care. Your answers will give us information about what issues women with mental illness may face and help us to figure out ways to overcome these barriers in order to improve your reproductive health and health care experiences.

1. Tell me a little bit about who you talk to and who you feel like you can talk to about sexual and reproductive health questions and issues?
    - a. Probe: Your intimate or sexual partner(s)? Why or why not?
    - b. Probe: What about medical professionals? Your mental health doctor? An OBGYN?

    c. Probe: Have you ever talked with someone specifically about birth control? Who? Tell me more about that.

2. How did you decide to become sexually active with the last person you had sex with?
3. Can you tell me about how you communicated the desire to become sexually active with the most recent person you had sex with?
4. Did your relationship change after becoming sexually active with the last person you have sex with? How so?
    a. Who initiated that change and why?

5. Where have you received education or information about how to prevent pregnancy or about using birth control? Tell me more about those.
    a. Probe: Do you feel like you understand all available birth control options and how you can access them.
    b. Probe: How about how to use different methods?
    c. Probe: What are some of the factors that have influenced your understanding? That is, why do you think you do or don't understand?

6. Now let's talk about your experiences with family planning services, such as care you've felt you needed or received for birth control, sexually transmitted infection testing or treatment, pregnancy or abortion. Tell me about some of those experiences.
    a. Probe: Describe the locations where family planning services have been sought or received (e.g. in mental healthcare settings, in reproductive health settings, in primary care settings, etc).
    b. Probe: What were some of the reasons for NOT seeking services.
    c. Probe: Describe some interactions with staff regarding counseling, communication, education, etc.
    d. Probe: Describe the types of contraceptive methods you've used and experiences with them.
    e. Probe: What were some of the reasons you've decided not to use or discontinued contraceptive methods.
    f. Probe: Describe experiences with pregnancy testing and decision-making (whether to keep the pregnancy or have an abortion).
    g. Probe: Describe experiences with needing or seeking abortion.
        i. Alternative based on answer to f: Describe experiences with seeking pregnancy care. Were you able to access prenatal care easily? Can you tell me about that experience? How pregnant were you when you started prenatal care?
    h. Probe: What were some of the reasons for NOT seeking abortion services or pregnancy care.

7. Describe how you treated by healthcare staff, including doctors, nurses, receptionists or other staff, during those encounters for family planning care.
    a. Probe: What were some of the supportive or positive experiences
    b. Probe: What were some of the unsupportive or negative experiences

II. Pregnancy intentions and pregnancy planning (both past and current)

1. We talked earlier about how many times you have been pregnant. Did you plan for those pregnancies and if so, discuss a little bit more about that process?

2. Tell me about any times that you became pregnant when you were not planning to.
    a. Probe: Were you taking birth control at that time? Why or why not.
    b. Probe: How did you feel about that (those) pregnancy(ies)?
    c. Probe: Did you attempt to get any prenatal care during the course of that pregnancy? Tell me about that experience.
    d. Have you ever had problems getting into prenatal care while you've been pregnant? Tell me more about that. What problems have you had starting or continuing prenatal care?
    e. Probe: Did you keep the pregnancy(ies) or have an abortion? How did you make that decision?
    f. Probe: Describe any healthcare experiences you had before, during or after those pregnancies. Was contraception ever discussed?

3. Let's talk more about abortion. How do you feel about abortion? Do you know anyone who has ever had an abortion? Have you ever had an abortion?

    a. Probe: How did you make that decision to have an abortion? Did you involve anyone else in that decision?
    b. Probe: Did others know about your decision and if so who? How did others treat you during that time? Why do you think they treated you that way?
    c. Probe: Tell me about your experience(s) seeking or receiving abortion service(s). Did you have support or difficulty in accessing abortion services? What were the factors that influenced this? What was the communication and care like from the health providers?

4. Have there been times in your life when you did not want to become pregnant but were afraid you would. If so, tell me about those times.
    a. Probe: Did you seek birth control services or methods to prevent pregnancy? If so, tell me more about that.
    b. Probe: How did you talk to your partner about your concern for pregnancy and preventing it

III. Perceived reproductive autonomy and interpersonal experiences with family planning decision-making and communication (with health providers, partners, parents, peers)

1. Tell me about your current intimate relationship(s).
    a. Probe: Do you have one or more steady sexual partner(s)? What about casual partners?
    b. Probe: In your relationship(s), who do you feel has more say about when you have sex, you or your partner? Why do you think that is?

   c. Probe: If you didn't want to have sex, would you feel comfortable telling your partner? Why or why not?
   d. Do you have sex with other people outside of an intimate relationship? Have you ever traded sex for money, food, or anything else?

2. How difficult or easy is it to talk to your partner about using birth control?
   a. Probe: Tell me about times when you have talked with or decided NOT to talk with a partner about birth control?
   b. Probe: Who has the most say about whether you use birth control, you or your partner? Why do you think that is?
   c. Probe: If you wanted to use a method, could you tell your partner? Why or why not.

3. Let's talk about how you make decisions about pregnancy planning.
   a. Probe: Tell me about times when you have talked or thought about getting pregnant or avoiding pregnancy with a partner.
   b. Probe: Have there been times when you have decided not to talk with a partner about it? Describe those.
   c. Probe: If you didn't want to get pregnant, could you tell your partner? Why or why not?
   d. Probe: If you became pregnant but it was unplanned, who would have the most say about whether you would raise the child, seek adoptive parents or have an abortion, you or your partner? Why do you think that is?

4. Tell me about experiences, if any, you've had in talking to a healthcare provider about how to prevent a pregnancy or birth control.

   a. Probe: What options for birth control methods were discussed.
   b. Probe: Do you feel like you received enough information about all available methods and options? Why or why not?
   c. Probe: Who do you think has the most say about whether you use birth control, you or your provider? Why do you think that is?
   d. Probe: Have you ever felt pressured to take birth control by your doctor? By anyone? Tell me more about that experience and what you decided to do
   e. Probe: Have you ever had a doctor tell you that you *have to* be on a certain birth control (or any birth control)? How did you feel about that?

5. Have your mental health specialists talked to you about birth control or pregnancy planning? If so, tell me about those discussions.
   a. Probe: How comfortable do you feel talking to your psychiatrist about birth control?

V. The potential role of stigma (e.g. mental, reproductive, interactive) in shaping reproductive health and healthcare experiences

1. Let's talk about how people treat you in general. Do you ever feel like you're treated a certain way by people around you? What about by your doctors?
2. Is it difficult for you to talk about your mental illness? Have you ever felt that someone treated you a different way because of it? How did you feel about that?
3. How do you feel about the care you receive from this clinic? How do you feel about the care you receive from other doctors?
4. Have you ever been hospitalized for your mental illness? How did you feel about the way you were treated during that time? How were you treated by your community when you were discharged?
5. When do most women in your community get pregnant and have kids? Tell me about how you think most women make that decision. How did you make that decision?
6. When you were pregnant, do you feel like you were treated a certain way by doctors and nurses because of your medical diagnosis? What about postpartum?

VI. Perceived logistical and social barriers that may preclude contraception and family planning service use.

1. Has there been a time when you have wanted to see a health care provider about your sexual and reproductive health or family planning issues but could not? Tell me more about that.

    a. Probe: What were some of the reasons, for example any related to transportation, costs, stigma and fear of disclosure, lack of support from partners or family, fear of providers' reactions or other reasons?

2. Have there ever been times when you wanted or needed birth control and were not able to get it? If so, tell me more about those times.
    a. Probe: What were the factors that influenced this?
    b. Probe: Have there been specific methods that you wanted but were not able to get. Which ones. Why couldn't you get the method(s)

Thank you so much for taking the time to talk to me about everything today. Is there anything else you want to talk about before we finish our time together?

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