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## Pregnancy and severe mental illness: Confounding ethical doctrines

JITENDER ANEJA, SONAM ARORA

### Abstract

*Pregnancy brings joy and excitement to some women, but great distress to those who suffer from severe mental illnesses like schizophrenia. Women with severe mental illnesses (SMIs) may have difficulty planning a pregnancy and deciding whether to continue to viability, and thence to term. Dilemmas also surround pharmacotherapy for this population, as (non)treatment is associated with its own challenges. The psychiatrist may have to make challenging decisions based on the principles of autonomy, beneficence, and relational ethics. Furthermore, there are ethical controversies inherent to the underlying pathologies, their non-treatment, and the various psychosocial factors that could impact parenting in such mothers. In addition, limited or ineffective use*

*of family planning, mental health services, and contraception often act as forerunners of these problems. Considering the sparse literature on this topic and the perplexing legal responsibilities pertaining to the recently implemented Mental Health Care Act, 2017, we have attempted to highlight the various ethical dilemmas that confront a psychiatrist while managing a patient from this group.*

**Keywords:** pregnancy, perinatal, severe mental illness, schizophrenia, psychosis, ethics

### Introduction

Ethical issues and psychiatric practice are the two sides of a seesaw, and are often difficult to balance, with pregnancy adding further complications to this intricate equilibrium. The well-being of a pregnant woman with a serious mental illness (SMI) is influenced by her underlying mental pathology, a plethora of pregnancy-associated psychiatric disorders, and various psychosocial etiological factors. In addition, her unborn child may be affected by the parents' genetic predispositions, pharmaco-treatment, and disrupted parental relationships. In these situations, while catering to the woman and her foetus, the psychiatrist needs to consider the severity of the mental illness, respect her autonomy, and take into account ethical issues. Advances in treatment and the improved sensitisation

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of specialists have led to better patient compliance, improved marital life, and increased responsiveness to family planning in this group. However, most pregnancies among women with SMIs are still unplanned (1). When antenatal and postnatal mothers with mental health problems seek psychiatric guidance in managing their pregnancies, it can create dilemmas for the psychiatric team. At times, the psychiatrists are put under duress, as the decision-making responsibility falls entirely on their shoulders (2). With the following case vignette, we raise certain pertinent questions related to perinatal mental health problems and discuss possible solutions.

### Case vignette

A 25-year old married woman who has been on antiepileptics since she was seven years old came in for an antenatal check-up and was referred to the department of psychiatry for symptoms relating to paranoia, lack of self-care, and muttering to herself.

Her condition had started deteriorating during the initial days of her marriage of two years. She was diagnosed with schizophrenia and epilepsy (which has since resolved). She was started on olanzapine with her informed consent and carbamazepine—which she had been taking without a prescription—was tapered and stopped. However, despite counselling her and her family, she dropped out of psychiatric care after two visits, and did not consult psychiatrists elsewhere. Furthermore, weathering the ongoing symptoms of paranoia, she took care of herself, observed precautions for the well-being of her yet-to-be-born child, and experienced limited socio-occupational dysfunction. At term, she delivered a healthy baby girl.

Her psychosis worsened 5–6 months postpartum, and her family brought her back for psychiatric consultation. They cited her movement to another catchment area as the reason for her dropping out, but could not explain her leaving psychiatric care. At the time of her second presentation, she had florid delusions of infidelity, reference, and persecution, along with auditory hallucinations, agitation, poor self-care, marked socio-occupational dysfunction, impaired sleep, and a refusal to eat. She also threatened to commit suicide because of her delusions. The child was being looked after by her mother and sister. In view of the severity of her illness and her lack of mental capacity, she was admitted under supported admission and with the consent of her husband and father. As she refused oral treatment, she was first treated with intravenous haloperidol and promethazine. In the absence of any advanced directives—and given her refusal to eat, severe psychosis, and suicidal threats—we initiated treatment with modified bi-temporal electroconvulsive therapy after educating her family and obtaining surrogate consent.

She was lactating at this time and the doctors could not elicit the date of her last menstrual period. During the course of therapy, she was prescribed a pelvic ultrasound for some other indication, and was found to be 12 weeks pregnant. At the time of this revelation, she lacked the mental capacity to understand

her situation, and therefore, the medical team told her spouse and family about her pregnancy and obtained revised consent for the continuation of ECT and pharmacotherapy.

Her brief psychiatric rating score reduced from 56 to 22 after four sessions of ECT, and she regained her mental capacity to make decisions for herself. After she learned that she was pregnant for the second time, she was ambivalent about continuing the pregnancy to viability. She expressed concerns about transmitting her illness to her child and the adverse impacts her medication may have on the unborn child. On further follow-ups she almost remitted, with only random ideas of infidelity, but the ambivalence towards continuing the pregnancy remained.

This case raised various questions pertinent to the care of a mother with SMI vis-à-vis her child and her unborn foetus. For the treating team, it entailed certain long-standing but unresolved dilemmas, which we mention below.

1. Should the patient continue or terminate the pregnancy?
2. Can we medicate against the woman's wishes, considering the effects of harmful untreated psychotic symptoms?
3. What are the parenting risks in mothers with SMI?
4. How do we address family planning in women with SMI?

The aforementioned questions are often linked to each other, and thus we will not address their answers in exclusion; rather, we will follow an integrated approach. In the following sections, we attempt to address these important aspects of perinatal mental health in patients with SMI.

### Deciding to continue the pregnancy to term

The twenty-first century saw a revolution in human rights, with rapid advances in women's reproductive rights. We now advocate for the right to reproductive health, including the right to abortions, for all women in most countries. Women with SMIs are more likely to terminate their pregnancies than non-psychiatrically ill mothers (4, 5). The factors that motivate this step include a lack of social support, inadequate finances to rear the child, fear of obstetrical complications, fear of parenting with mental illness, and the possibility that the child may be at increased risk of mental illness (6). There has been sparse research on the medical ethics of decision-making in the case of pregnant females with SMI. This research is further hampered by different abortion legislations across the globe (7). The last two to three decades have seen some advancements in this field and framing of clinical guidelines and recommendations concerning the identification and management of unwanted pregnancies and the management of pregnancies in patients with SMI (8–10).

The forerunners in this research arena, McCullough et al (11), have proposed an ethical framework for decision-making in cases involving pregnant women with schizophrenia. It consists of five components: (i) chronically and variably impaired autonomy; (ii) assisted decision-making; (iii) surrogate decision-making; (iv) strategies for dealing with the physician's

feelings in response to these patients, and (v) the concept of the foetus as patient. The authors aptly try to balance the principles of beneficence and patient autonomy in the process of decision-making. They state that “respect for autonomy is an ethical principle that obligates the physician to empower the patient’s decision-making capacity by providing information about medically reasonable alternatives for the management of the patient’s condition” (11). Beneficence is defined as an “ethical principle that obligates the physician to seek the greater balance of clinical goods over clinical harms in the outcomes of patient care” (11). Beneficence-based clinical judgement should be evidence-based. To put it simply, we need to make sure that we keep the patients’ right to choose intact, while simultaneously taking the course of action that most benefits them. However, authors like Dudzinski (12) emphasise the patient’s autonomy in decision-making. They do not provide enough weightage to the concept of foetus-as-patient, and therefore, this model proposes that the woman should take the primary decision to continue or terminate her pregnancy.

McCullough and Chervenak (13) have described a shared decision-making model in which the patient, surrogate (ie a family member/caregiver or a nominated representative), and psychiatrist interact throughout the decision-making process. First, the psychiatrist must ask the patient her beliefs about her condition, diagnosis, prognosis, and alternative management protocols. Next, the psychiatrist must correct factual errors and simultaneously supplement the patient and surrogate’s knowledge. They must explain the basis for their clinical judgement regarding all available management protocols, including the wait-and-see approach. With the assistance of the psychiatrist, the surrogate and patient must develop a holistic understanding of her mental condition and the treatment protocols. Finally, they must reach and implement a mutual decision. A recently published international position paper (14) emphasises such a model of decision-making and lays down detailed guidelines to address various aspects of pregnancy-related issues in persons with SMI.

In the Indian context, the Mental Health Care Act, 2017 (or MHCA), also recommends respecting the rights of patients and their autonomy in the decision-making processes pertaining to their mental health problems. It also empowers patients with mental illness through the concepts of informed consent and mental capacity. But the MHCA has failed to address the intricate issues of perinatal mental health.

In the above case, at the time of second presentation, the patient had impaired autonomy owing to acute psychosis. The treatment team made attempts to reinstate her mental capacity with the help of pharmacotherapy and biological treatment, both of which they administered with the intention of minimising the impact on the foetus according to the available evidence (15–17).

### Pharmacotherapy of pregnant women with psychosis

Pregnancy often motivates patients to give up prescription medications out of concern for the unborn child (18). The

decision to stop or continue pharmacotherapy during pregnancy—often based on various factors like educational level, underlying psychopathology, severity of symptoms, societal pressure, and cultural values—is difficult for any woman. The situation may be further complicated in cases of SMI, which are already plagued by exploitation, victimisation, lack of social support, and compartmentalised delivery of medical health services (10). Although patients with SMI have normal pregnancies and deliveries, they are at increased risk of adverse obstetric outcomes (19). Hence, the question arises: considering the effects of harmful and untreated psychotic symptoms, is it ethical for caregivers and medical professionals to impose treatment against the patient’s wishes?

Firstly, as in other decision-making, the general principle is that the patient should be able to decide if she wants to seek treatment and to choose the nature of treatment. The situation gets complicated when a patient with psychosis refuses treatment that the clinician believes is essential (20, 21). These ethical concerns are further exacerbated when we apply the principles of relational ethics—that is, when the patient and her baby’s well-being are intertwined (22). Relational ethics is defined as “moral responsibility within the context of human relations, [that] recognizes the human interdependency and reciprocity within which personal autonomy is embedded (23). However, we recommend applying this principle without undue coercion or medical paternalism, and with respect for the patient’s autonomy, except in situations where it is evident that the benefits of the proposed treatment are clear and overwhelmingly beneficial for the foetus (5, 20). But the literature is replete with ethical and legal cases where the pre-viable foetus is not considered a person/patient, and only the mother’s autonomy is considered (11).

The Mental Health Care Act, 2017 (3) has various provisions for admission of different categories of patients. It states that only patients with mental capacity (S 4, Chap II) to make decisions can be admitted independently; incapacious patients or those who require high support for decision-making shall be considered for supported admissions (Ss 89, 90). The Act recommends that those under supported admissions be reviewed periodically, and that treating teams seek informed consent from them once they regain their decision-making capacity. Unfortunately, it leaves certain pertinent issues—like the lack of insight, the psychopathology that affects the patient’s decisions, and guardianship—unaddressed (24). Also, the situation is murkier if the patient writes an advance directive to not receive certain forms of treatment, viz. electroconvulsive therapy—which could, in fact, be the only form of effective treatment in certain situations, like the one under discussion. However, the American Medical Association (AMA) provides a middle path: it suggests that respectful persuasion and close legal and clinical ethical consultation can guide treating teams through this dilemma.

Secondly, the pharmacotherapy of pregnant women is another grey area, as none of the anti-psychotics have been approved by the US Food and Drug Administration (USFDA) or the

Central Drugs Standard Control Organisation (CDSCO) for India. The limited data on the safety of various psychotropic medications, antipsychotics included, is available in case reports/series and retrospective studies. Also, research in this population has various ethical and legal ramifications beyond the scope of our discussion. The literature supports the use of second-generation antipsychotics, such as olanzapine, as well ECT in pregnant women with SMI and shows that it does not increase the risk to the foetus in comparison to in healthy pregnant women (15-17). Besides, various professional bodies involved in this field, including the American Congress of Obstetricians and Gynecologists, recommend that pharmacotherapy for SMI during pregnancy be continued for the betterment of the patient as well as her foetus (25).

In the case described previously, even though the treating team educated the patient and her family about her mental condition, they did not follow up or continue with medication during the first pregnancy. At her second presentation, the patient lacked the mental capacity to make decisions about treatment; she appeared to be in a state that was harmful for her as well as the foetus. She was therefore treated after the consent of her family. Once she regained her mental capacity, the treating team sought her consent. However, the big task ahead for the treating team will be to keep her in treatment and deal with the ethical issues pertaining to further treatment as and when they arise.

### **Parenting risks in mothers with SMI**

A mother with SMI who has recently delivered is at increased risk of developing postpartum psychosis, depression, anxiety, and other child-related disorders. There is a nearly 25% prevalence rate of postpartum psychosis in women with a prior history of schizophrenia (26), and this is mainly due to discontinuation of prescription medication during pregnancy or lactation (27). Hence, a mother with psychosis/schizophrenia elicits various biases during a physician's assessment of her parenting capacities. Certain research has shown that mothers with SMI have impaired capacity for parenting because of their psychopathology (28, 29); studies also show that infant-mother interactions are also deficient in this group (26, 30, 31). The predictors of social service intervention or mother-infant separation include a diagnosis of schizophrenia or other SMI in the mother; low socio-economic status; a psychiatric illness in the partner and a poor relationship with the partner; ethnicity; neonatal complications; previous child or children; single-parent status; and legal problems (32). However, this study mainly incorporated European studies which found a weak association of African-Caribbean ethnicity of mothers with an increased risk of poor parenting outcomes. Furthermore, this association was partly attributed to high prevalence of single parents in African-Caribbean families in comparison to other ethnic groups and that it was also associated with poverty and social class. However, mothers with acute psychosis have shown better mother-infant interactions and lower risks of displacement than mothers with schizophrenia (33). Despite the evidence that most mentally ill mothers do not abuse

their children, it remains a significant variable in the history of maltreated children (34, 35). Apart from the parent's mental illness, the child's inherent genetic predisposition to suffer from mental illness is a double whammy.

However, ethical principles dictate that one cannot hold women with mental illness to a different standard of parenting than those without mental illness. Laura Miller (36) highlights the dilemma of a physician obliged to look out for the welfare of the "not yet conceived child" whom they believe to be at high risk of maltreatment at the hands of a mother with psychotic illness. According to her, a physician shall attempt counselling the woman about the risks that her mental illness poses to the potential mother-infant relationship. Moreover, women with mental illness must be given access to treatment in the form of psychosocial rehabilitation, parenting skills training, enhanced social support, and other relevant measures in case they conceive. Brockington and others (14) recommend a multi-disciplinary intervention, which should be tailor-made according to the available resources and may include a general practitioner, representatives of obstetric and mental health teams, and social workers, apart from the expectant mother and her family. Only the United Kingdom recognises perinatal psychiatry, which deals specially with perinatal mental health disorders, as a sub-discipline of psychiatry. In other countries, it still awaits recognition among health professionals as well as users. Brockington et al (14) highlight the need for this specialty and propose apt guidelines as well. Disappointingly, no nation has been able to fully address mother-child health needs thus far.

The Mental Health Care Act, 2017 (3) has touched upon this subject briefly by implying that women with SMI receiving care at mental health establishments shall not be separated from their children of less than three years of age. However, if the psychiatrist finds that there is a risk to the child in any form, the child can be separated from the mother, but not for more than 30 days. Nevertheless, as prudent as this may sound, it has failed to address the issue of the child's guardianship in such cases.

In the case of the patient in this study, the concerns that she shared, like the risk of transmission of her illness to her children and the burden of parenting two young children, did put the treating team on shaky ground. However, after the treating team educated her about her illness and highlighted various positive factors, such as the achievement of near-complete remission, the presence of good insight, her adaptive skills, the availability of family support, her financial abilities, and her commitment to engage in further treatment, the patient could make decisions for herself and continue the present pregnancy to term.

### **Family planning in mothers with SMI**

Mothers with SMI are largely underserved in the area of family planning, and there is very little research on this topic. This population receives limited family planning services because

of negative attitudes towards their desire for children, lack of knowledge of established guidelines, unwillingness to discuss family planning, and the absence of reproductive autonomy. Many believe that due to a range of factors—particularly the illness, psychotropic medications, and institutionalisation—persons with SMI engage less in sexual activity and have lower fertility than the general population (36). However, de-institutionalisation, provision of community psychiatry services, innovation of newer neuroleptics, and changes in societal attitudes have led more persons with schizophrenia to marry, and thus have increased chances of pregnancy in this group. One of the earliest studies on this from China, which in the 1980s directed people to follow the one-child norm, reported that the rate of birth control was poor in patients with schizophrenia (females more than males) as compared to the healthy population; the author suggested sterilisation as the foremost method of birth control in females with schizophrenia (37).

Some other surveys also revealed that women with SMIs did not want to become pregnant, but did not use contraception (38, 39). A recent study (40) found that women with mental disorders had an average of three pregnancies, of which two were unplanned. Furthermore, they used less effective methods of contraception. Despite a clear need for family planning counselling in psychiatric settings, it is rarely provided in conjunction with mental health services. Ariela Frieder established guidelines for pre-conception counselling for women with SMI; they cover the identification and treatment of risk behaviour; boosting the patient's knowledge of the risks to mother and child; developing and improving parenting skills; and mobilising support systems (41). A 2009 Indian study from Bengaluru (1) stated that only 18% of the 135 women registered for a mother-child psychiatry service were referred for pre-pregnancy counselling because of the discordant psychiatrist-patient ratio, unwillingness to disclose pregnancy concerns to a male psychiatrist, and less control of the women over contraception. A decade after this study, and despite recent legislation (MHCA 2017), the situation on the ground remains the same. Although the present MHCA advocates for the rights of mentally ill patients, it has remained silent on the reproductive rights of women with SMIs.

Even though treating psychiatrists often avoid prescribing potentially teratogenic psychotropics to women in the reproductive age group, they often miss out on providing family planning counselling or referring them to an obstetrician for it. Coverdale and others (42) recommend strategies for persons with mental illness to prevent unwanted pregnancies. These include education about resisting unwanted sexual advances, contraception use, the possible benefits and risks of pregnancy, and advocacy of condom use among male partners. A few studies undertaken nearly 50 years ago in some psychiatric hospitals in the US (43, 44) emphasised the acquisition of informed consent for contraception, the importance of voluntarism, and the usage of reversible methods of contraception. Although the

presently available long-term and reversible contraceptives may prove to be very successful among this population, but their non-removal on request of patients, or utilising coercion or manipulation in view of the principle of beneficence may be outweighed by respect for the patient's autonomy despite an impaired decision-making (8).

## Conclusion

Pregnancy in women with SMIs poses challenges to both the patient and the psychiatrist. The underlying psychopathology, pregnancy-induced SMI, pharmacotherapy, and other psychosocial factors make gestation arduous for the patient. On the other hand, respect for autonomy and beneficence, along with numerous ethical and legal issues, create several hurdles for the psychiatrist. Understanding and assessing the patient's decision-making capacity, and the involvement of family members in decision-making throughout pregnancy and intrapartum and post-partum, is the most crucial step in treatment. Thus, psychiatrists need to understand the patient's wishes and explain the available management strategies and her condition to her to reach a mutual decision. This must also be applied postpartum to improve the mother-child relationship and the mother's parenting skills. Further, pregnancies in this study group are often unplanned. Hence, the psychiatrist must educate the patient as well as the partner on the risks that both mother and child face when the mother is on medication while pregnant. Furthermore, they must create awareness about different contraceptive methods in these patients.

## Future directions

Perinatal psychiatry is still an unexplored area of specialisation; it is largely at an infant stage even in developed nations. Lack of public awareness, insufficient mental health services at the grassroots level, and low clinician interest in this area are some of the reasons for an insufficient knowledge base. Despite all the hindrances, a group of researchers have made some progress in this field (8–10, 14). Furthermore, the integration of mental health services with other services like social services, child protection, public health, and medico-legal services, is the need of the hour. Like other mental health services, some of these services are highly localised, underdeveloped, and not easily accessible to the common people—especially the Indian population—and often require the patient/caregiver to bear the expenditure (45–47). However, a few centres, like the National Institute for Mental Health and Neurological Services (NIMHANS) at Bengaluru, have been successful in organising such teams. They have been providing perinatal mental health services for more than a decade. The same model may be replicated, at least at some well-developed tertiary care psychiatric centres. Furthermore, the Government of India, through the Mental Health Care Act, 2017, has envisioned the provision of community rehabilitation services for those affected by various mental health problems. So, in the future, this could provide the required manpower to establish perinatal mental services.

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## Administering drugs to an individual in a non-pathological situation: The Caster Semenya case

JAGADEESH N

### Abstract

*The International Association of Athletics Federations (IAAF) has barred individuals whose circulating testosterone levels are higher than 5 nmol/L from competing in women's competitions in middle-distance track events. To become eligible, they must take anti-testosterone treatment to achieve the appropriate testosterone levels. The 2019 decision of the Court of Arbitration for Sport has brought the spotlight back on Caster Semenya's case and on the ethics of testing the testosterone levels of sports persons with or without consent, imposing anti-testosterone treatment in order to qualify to participate in sports competitions for females. This article debates all the issues concerned from various perspectives.*

**Keywords:** Testosterone levels, intersex variations, DSD, IAAF rules, sex verification tests, anabolic effects.

### Background

Caster Semenya is a South African Olympic athlete who was asked by the International Association of Athletics Federations (IAAF) in 2009 to undergo sex verification tests to prove herself female. She was prevented from competing in world athletics events till the IAAF deemed her eligible to compete in 2010. The Caster Semenya case is in the news again (1); but this time the medical community is also involved in the debate. The Court of Arbitration for Sports (CAS) upheld the IAAF regulation (1,2, 3) that individuals must have testosterone levels below 5 nmol/L to compete as females. Otherwise, they

must take treatment to lower their testosterone levels. This brings us to a debate on several ethical issues.

### What is the available research evidence on the issue of testosterone levels and their impact in sports persons having DSD (Differences in Sex development)?

Testosterone levels improve individuals' anabolic effects, muscle building abilities, and confidence levels (4). Whenever there are higher levels of circulating testosterone in a female with properly functioning androgen receptors, there is a definite increase in muscle mass and muscle strength, circulating haemoglobin levels, and thus, sporting potential (3). Hence, IAAF has restricted the eligibility to compete in women's competitions based on circulating testosterone levels to remove any unfair advantages in the 400 m to one mile middle distance track events (5). It also specifies waiting for a six-month period after the administering of anti-testosterone treatment to remove any residual effect of the high testosterone levels (2,3) in sports persons with DSD.

### Are all individuals with DSD or hyperandrogenism barred from all sports competitions?

As per IAAF guidelines, individuals with differences in sex development (DSD) or hyperandrogenism are not barred from all sports competitions. The IAAF has clarified (2) that only for international competitions, individuals with the following DSD are barred from competing in the female category in distance track events (400 m to a mile distance) in both individual and relay competitions: 5 $\beta$ -reductase type 2 deficiency, partial androgen insensitivity syndrome (PAIS), 17 $\beta$ -hydroxysteroid dehydrogenase type 3 (17 $\beta$ -HSD3) deficiency, ovo-testicular DSD, any other genetic disorders involving disordered gonadal steroidogenesis. In addition, to be barred, individuals with DSD should have circulating blood levels of testosterone above 5 nmol/L and sufficient androgen sensitivity for the testosterone levels to have a material androgenising effect. Female athletes exhibiting hyperandrogenism (polycystic ovarian syndrome and androgen insensitivity syndrome) (3) are not barred, as their circulating blood levels of testosterone are below 5 nmol/L. This standard of 5 nmol/L could be because of IAAF

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