Assisted and Surrogate Decision Making for Pregnant Patients Who Have Schizophrenia

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Abstract

Because of a dearth of literature, we developed preventive ethics strategies for managing the pregnancies of patients with schizophrenia. Schizophrenia can chronically and variably impair a woman's decisions concerning the management of pregnancy, including the decision about whether to continue the pregnancy through to viability and term. The psychiatrist must balance autonomy-based and beneficence-based obligations to the pregnant woman with schizophrenia, and both the psychiatrist and pregnant woman have beneficence-based obligations to the fetus when the fetus is a patient. We discuss the assessment of the decision-making capacity of pregnant patients with schizophrenia and describe the strategies of assisted decision making that aim to diminish chronically and variably impaired autonomy. When patients are severely impaired in decision-making capacity, as, for example, in psychotic denial of pregnancy, the standard of surrogate decision making applies. This should be guided by the substituted judgment standard. When patients' values are not known or have not been consistently held over time, surrogate decision making should be guided by the best interests standard. These strategies should substantially enhance patients' autonomy in the psychiatrist-patient relationship and contribute to the quality of their psychiatric and obstetric care.

Keywords: Schizophrenia, pregnancy, preventive ethics, chronically and variably impaired autonomy.


The clinical management of pregnant women with schizophrenia can present major ethical dilemmas to psychiatrists. The challenges concern how to respect the patient's autonomy while also helping her to prevent possible adverse consequences for herself and the pregnancy. Schizophrenia has a median age of onset during the childbearing years for women (APA 1997). Pregnant women with schizophrenia have somewhat higher rates of obstetric complications (Spilvogel and Wile 1992; Sacker et al. 1996), congenital malformations in the fetus, and postneonatal deaths (Jablensky et al. 2000; Bennedsen et al. 2001) compared to the general population. Furthermore, there is evidence that patients with major mental disorders including schizophrenia are more likely to have induced abortions than are nonpsychotic women (Miller and Finnerty 1996; Coverdale et al. 1997b). Many patients who carry their pregnancies through to term eventually lose custody of their children either to family members or to child protective services that arrange for foster care or adoption (Coverdale and Aruffo 1989; Coverdale et al. 1997b), and the progeny of those with schizophrenia are more likely to develop schizophrenia (APA 1997).

There is, however, a paucity of literature concerning the ethical issues in the management of schizophrenia during pregnancy, particularly in managing termination of pregnancy decisions. Therefore, one goal of this article is to recommend strategies for psychiatrists and other mental health professionals to help manage the ethical issues in treating psychosis during pregnancy. This is based on our earlier finding that patients with schizophrenia may manifest impaired decision making to varying degrees over time (McCullough et al. 1992, 2002). We also discuss the relevance of the concept of fetus as patient and describe preventive ethics strategies (Chervenak and McCullough 1990), including assisted and surrogate decision making, that can prevent ethical conflicts in decision making concerning the management of pregnancy in patients with schizophrenia. We illustrate these strategies using three cases based on clinical experience.
Case Presentations and Ethical Analysis

Case 1. A 30-year-old unemployed woman of no fixed abode was admitted when acutely psychotic. She had a history of schizophrenia and multiple previous admissions, although she had had minimal if any contact with psychiatric outpatient clinics and had been poorly compliant with treatment recommendations. She was discovered to be pregnant and at about 13 weeks gestation, and she had no supportive male partner. She had indicated an earlier desire to become pregnant but now requested a termination of pregnancy because of "bad vibrations" from the pregnancy.

The first decision concerning pregnancy that any woman must make is whether to continue the pregnancy to viability and then to term. One matter to clarify is whether psychosis may have adversely influenced the patient's ability to make this decision and may have impaired her capacity to validly participate in the informed consent process. It is crucial for the psychiatrist to evaluate the extent of the effect of psychosis on this decision, because the psychiatrist is obligated to respect autonomy by acknowledging the patient's values and beliefs, by eliciting her preferences, and by carrying out those preferences (unless there are ethically compelling reasons to the contrary) (McCullough and Chervenak 1994).

The psychiatrist, however, is also obligated by the principle of beneficence to seek the greater balance of goods over harms in caring for a pregnant woman and fetal patient, as judged from a well-informed and rigorous or evidence-based clinical perspective (McCullough and Chervenak 1994). Thus, the psychiatrist should also consider possible adverse effects of psychosis on both the pregnant woman and the fetus when the fetus is a patient.

In this case, in our opinion, the patient's exercise of autonomy in making a decision about whether to proceed with the pregnancy is the major ethical consideration. This is because, as two of the authors have previously argued, not all fetuses are patients (McCullough and Chervenak 1994). A pre-viable fetus is a patient only when the pregnant woman confers the moral status of patient on the fetus, something that she is free to do or not to do as a function of her values, beliefs, and preferences. The only link between a pre-viable fetus and its later achieving moral status as a child is the pregnant woman's autonomy, exercised in the decision not to terminate her pregnancy and to present the pre-viable fetus and herself to the physician (McCullough and Chervenak 1994). The advantage of the concept of the fetus as patient is that it does not make reference to "fetal rights" and therefore keeps decision making for this patient population insulated from the quagmire of abortion politics.

With this proposed ethical framework in mind, we turn now to consider the exercise of autonomy by patients. To participate in the informed consent process, patients must first be able to attend to, absorb, retain, and recall the information disclosed. The psychiatrist should aim to provide the information to the patient in language the patient can understand and at a pace the patient can manage. The patient needs to reason from present events to their future likely consequences, which is called cognitive understanding (White 1994). She needs to understand that these consequences could happen to her and her fetus (and future child, should her pregnancy continue through delivery). This is called appreciation and is based on the work of Grisso and Appelbaum (1998). She should be helped to evaluate those consequences on the basis of her own values and beliefs—that is, to achieve evaluative understanding (White 1994). In our opinion, the psychiatrist should aim to help the patient achieve cognitive understanding, appreciation, and evaluative understanding, and to communicate a voluntary decision (Faden and Beauchamp 1986; Roberts 2002) based on these types of understanding.

In earlier work, we argued that a patient's ability to participate in one or more of these steps may be chronically impaired. In addition, in patients with schizophrenia or depressive disorders this impairment may vary over time, resulting in a phenomenon we have termed chronically and variably impaired autonomy (McCullough et al. 1992, 2002; Coverdale et al. 1993, 1996, 1997a).

In our view, the concept of chronically and variably impaired autonomy has several important implications for the case reported above. First, the patient's potential areas of deficit in participating in the informed consent process should be assessed. For example, the patient's comment that she was experiencing "bad vibrations" may relate to her experience of quickening and may reflect a simple lack of understanding of this phenomenon. The comment also suggests a possible paranoid perception of the pregnancy. Paranoia can, in turn, impair her ability to attend to, retain, and recall relevant information about the pregnancy, by significantly distracting her. Most important, paranoia may chronically and variably disrupt the capacity for evaluative understanding by her thinking, for example, that the fetus is somehow a frightening entity or that it is alien and needs to be expelled, or that health professionals intend to harm and not to help her. When present, auditory hallucinations may also distract a patient and impair attention and absorption, recall, or retention of information. Auditory hallucinations can impair evaluative understanding and voluntariness when they command her to hurt herself or the fetus or to terminate or continue the pregnancy.
A second important implication of chronically and variably impaired autonomy is that reversible barriers to the patient's exercise of autonomy should be identified and addressed. The strategies of education, medication, and psychosocial interventions such as teaching problem-solving strategies and communication skills training enable the overcoming of barriers to the exercise of autonomy and constitute assisted decision making. For example, education may contribute to ameliorating a patient's anxiety about the experience of quickening. Patients might also be educated about their own disorder, how it might have contributed to difficulties in decision making, and particularly how paranoia can influence evaluative understanding and contribute to a wish to terminate the pregnancy. Educational interventions—including corrected feedback, multiple learning trials, and organization or simplification or repetition of key elements in consent forms—might remedy deficits in understanding (Dunn and Jeste 2001; Jeste et al. 2003). Medications constitute an important response to impaired decisions brought about by paranoia or auditory hallucinations. A small increase in the risk of congenital malformations with low-potency antipsychotic medications has been identified, although less is known about higher potency and newer antipsychotic agents (Altshuler et al. 1996), so the potential risks must be considered along with the potential benefits. Problem-solving strategies and communication skills training can assist the patient by reducing psychosocial stresses and by reducing the possibility of future illness episodes, by contributing to stability of her values and beliefs, and by enhancing her ability to become a more effective advocate for her own preferences (Falloon et al. 1998). Treatment of impaired autonomy might also include treatment of a concurrent physical illness or of substance abuse when these conditions relate to the impairments.

This case also highlights issues that arise when a patient with schizophrenia appears to reverse her decision about whether to proceed with a pregnancy. In this case, the change in decision might have been related to the onset of paranoid feelings about the fetus, reflecting the variability of impaired autonomy. Another similar and perhaps not uncommon scenario may occur when a patient with schizophrenia changes her mind and decides not to take medications when pregnant. Assessment might determine whether the patient changed her decision because of a psychotic decompensation—that is, because of undue paranoia and overestimation of the possibility of adverse consequences of medications for the pregnancy.

In our view, in such cases the priority in management should be to assist the pregnant woman by inviting her to consider her previous values regarding the pregnancy and motherhood. She can then be assisted in a decision, based on her values, and using the principles of assisted decision making as outlined above, about whether to continue the pregnancy to viability and to term. In some cases, it may even be possible and appropriate for the psychiatrist to ask a patient when relatively unimpaired in decision-making capacity by psychosis to state her preference for the outcome of the pregnancy, given the possibility of a subsequent increase in the level of paranoia or psychosis. Such a declaration in the form of a "Ulysses contract," in which consent for measures to avoid risk that is given when a patient's decision making is relatively less impaired can be applied to situations in which decision making may become more impaired (Winston et al. 1982). Ulysses contracts are reversible and not legally binding, and at all times the pregnant woman should be assumed to possess adequate decision-making capacity. Ulysses contracts assist by reminding the patient of her earlier preferences in an attempt to enhance her decision-making capacity.

These strategies of assisted decision making are intended to prevent unjustifiably taking over a patient's decision making about the pregnancy to avoid possible adverse consequences. Assisted decision making in our view therefore serves to prevent unwarranted control of patients' decision making by physicians, family members, and institutions. Assisted decision making also helps counter the possibility that a patient's initially expressed views or preferences will be interpreted as authoritative—as though they are based on the patient's preexisting values and beliefs.

**Case 2.** A 25-year-old woman with a history of multiple previous admissions, a diagnosis of schizophrenia, poor functioning, and no stable residence was readmitted for evaluation. She had had two previous pregnancies, including a termination of pregnancy, and another child who was lost to custody. She was discovered to be pregnant at an estimated 10 weeks gestation and had the delusional belief that she was not pregnant. She had claimed that she was coerced into sex, that the baby was not hers, and that she would be punished. She had been forced into sex and presented as severely thought-disordered, vague, and paranoid.

Denial of pregnancy is uncommon, although the diagnosis of schizophrenia likely constitutes an important risk factor (Miller 1990). Such a pregnancy is high risk by definition; psychotic denial of pregnancy is associated with poor prenatal care and precipitous or unassisted delivery (Miller 1990). Patients with major mental disorders including schizophrenia also sustain a higher risk of being coerced or forced into sexual intercourse compared to a comparison group (Coverdale and Turbott 2000).

Psychiatrists should also be aware of the possibility that the patient may be HIV-positive (Coverdale et al. 1997b) and should assiduously search for other factors.
that may contribute to psychosis and impair decision-making capacity, then seek to treat reversible impairments. Psychotic denial of pregnancy may vary in severity over time and can be ameliorated by treatment with neuroleptics (Miller 1990). These considerations warrant providing her with opportunities over time to express her views about the pregnancy and its management.

In our view, it is unlikely that giving her more time will succeed in this case, because a severe impairment in cognitive understanding and appreciation will severely limit the patient's evaluative understanding. The patient cannot meaningfully participate in decision making when the possible consequences of the pregnancy she is to assess on the basis of her own values and beliefs are denied. The patient would also not be able to take account of the effects of her behavior on the pregnancy (e.g., should she fail to allow assessments by an obstetrician or fail to comply with recommendations, or abuse illicit substances or alcohol).

The ethical standard of substituted judgment for surrogate decision making requires that decisions be made for the patient based on information about the patient's long-standing values or preferences, so long as those can be reliably identified. That is, the surrogate should, to the extent possible, make the decision the patient would make were the patient able to do so (Buchanan and Brock 1989). The patient's values, however, may not be known or discoverable, or may not have been held consistently over time. In this case, surrogate decision making should be guided by the best interests standard (Buchanan and Brock 1989), that is, identifying clinical management that protects and promotes the patient's health. Physicians should identify the legally appropriate surrogate decision maker. As we have previously argued (McCullough et al. 2002), the risks to the pre-viable fetus of continuing pregnancy, even if serious, are not predictable with any degree of certainty. Therefore, a justification for termination of the pre-viable pregnancy cannot be based on the grounds of protecting the fetus's health. The woman's health becomes the main focus of the best interest-based surrogate decision.

**Case 3.** A 35-year-old patient with a history of schizophrenia and multiple previous hospitalizations for paranoid delusions and aggressive behavior toward others was psychiatrically assessed when in her fifth pregnancy at 28 weeks gestation. She had had a history of physical and sexual abuse and had recently broken up with a former boyfriend. Her previous pregnancies had resulted in a miscarriage, a termination of pregnancy, and two children being taken into custody by the court within the first year of life because of a history of neglect. The patient wanted another child and had little conception of why others were concerned about her ability to parent.

The concept of the fetus as a patient is relevant to case management when the fetus is viable. The viable fetus without lethal anomalies constitutes the second sense of fetus as patient (McCullough and Chervenak 1994). Viability begins at about 24 weeks, when the fetus can exist independent from the pregnant woman with the assistance of technological interventions. When the fetus can survive ex utero, both the psychiatrist and the mother have beneficence-based obligations to the fetal patient (McCullough and Chervenak 1994).

This understanding should facilitate a discussion on how to protect the health and life of the fetus. The psychiatrist should aim to balance fetal beneficence-based obligations with beneficence-based and autonomy-based obligations to the pregnant woman. A thorough evaluation of her future parenting capacity is warranted (Steadman et al. 1994; Jacobsen et al. 1997) in an effort to identify possible deficits in advance and to remedy these through education, social support, and training. Psychiatrists should appreciate that even when women have lost custody of their children because of abuse or neglect, evaluation of parenting competency is rarely cut-and-dry, and some mothers may raise subsequent children successfully (Jacobsen and Miller 1998). Subsequent to the child's birth, evaluations of maternal competency require a sensitive and non-judgmental inquiry into maternal behaviors and thoughts, with data collected from multiple sources (Nair and Morrison 2000).

In our view, the psychiatrist should also adopt the preventive ethics strategy, in collaboration with colleagues in obstetrics, of discussing intrapartum management in advance with the goal of enhancing the patient's future autonomy. This discussion could present the various alternatives for managing labor and delivery. The patient's values about these alternatives could then be elicited, along with her evaluative understanding of the alternatives and her value-based preferences. An appropriate management plan based on those preferences should be negotiated. The patient should also be educated about what might constitute compelling and acute fetal or maternal indications that warrant delivery by cesarean section.

**Conclusions**

The clinical management of pregnant patients who have schizophrenia can be very challenging when decision making is impaired by delusions or hallucinations, formal thought disorder, or even denial of pregnancy. We have argued that when the fetus is pre-viable, the psychiatrist has an ethical responsibility to assess the attitude of the patient with schizophrenia toward the pregnancy and motherhood. Impairments in the steps of decision making, particularly in cognitive understanding, appreciation, and
evaluative understanding, should be identified. The preventive ethics strategies of assisted decision making help patients overcome the variable impairments of chronically and variably impaired autonomy in psychosis. Assisted decision making is also an important alternative to ethically problematic responses of taking over a patient's decision making and to treating the patient's decision about the pregnancy and its management as authoritative. Standards of surrogate decision making will apply when the patient is so severely impaired in decision making that she consistently denies her own pregnancy.

Psychiatrists may have strong feelings about the issues at stake for the pregnant woman with schizophrenia, both concerning her management of the pregnancy and her own health, and concerning her ability to adequately parent her prospective child. Psychiatrists understandably may experience frustration when patients exhibit inconsistent attitudes and views about the issues at stake, or foreboding about any patient's ability to make safe decisions for the fetus as a patient and prospective child. Such strong feelings can sometimes unbalance clinical judgment and the implementation of the strategies of assisted decision making (McCullough et al. 2002).

In responding to these strong feelings, it is important to realize that most patients with schizophrenia can successfully rear children, especially when given adequate support. Finally, addressing chronically and variably impaired autonomy aims to support the woman's autonomy-based prerogative to make thoughtful and well-informed decisions.

References


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