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ETHICS CASE

Medication Refusal in Schizophrenia: Preventive and Reactive Ethical Considerations

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Abstract

Clinicians treating patients with recurrent psychosis should encourage contingency planning with patients and families for how to respond to potential recurrences. Whether or not patients create a formal psychiatric advance directive, patients, families, and clinicians will be better prepared to deal with emergencies if they include "scenario planning" as part of ongoing clinical care. In the case under discussion this was not done, resulting in an ethical conundrum as to whether it was ethically justifiable to override the proxy decision maker's refusal of medication. Law on this question is unsettled, but the author argues that from the perspective of ethics, overriding medication refusal is sometimes ethically permissible.

Case

Charlie, a 55-year-old man with a history of schizophrenia, had been stable and functioning for more than a decade. Due to his significant concerns regarding the adverse effects of antipsychotic medications, he discontinued pharmacological treatment in close collaboration with his psychiatrist two years ago. Until recently, he was able to function well without medications and reported feeling much healthier overall, despite some worsening of his psychiatric symptoms. In particular, he was able to lose a significant amount of weight and no longer suffered from lipid and blood sugar abnormalities that he was experiencing while on antipsychotic medications. He continued to meet regularly with his psychiatrist throughout this period, and with the support of his wife, Reina, and his adult daughter, Laura, he and his psychiatrist developed a plan to enable a medication-free lifestyle that involved biweekly visits with a therapist and regular engagement with a community support group. He has repeatedly expressed his desire to avoid all medication treatment in the future.

Two weeks ago, his schizophrenia symptoms worsened, and he began experiencing paranoid delusions. He was involuntarily hospitalized after he attacked Laura, accusing her of being an imposter. Out of respect for his desire to avoid medications, his inpatient treatment care team tried to manage his care without medications. After two weeks of this inpatient approach, however, he remains psychotic and a significant risk to others.

Laura and the inpatient treatment team wonder whether it's possible to reintegrate him into his family and community without at least a short stabilizing course of antipsychotic medication. Reina, however, supports his choice to continue to refuse medication and, in a family meeting, reminds Laura and the treatment team that while Charlie does not have capacity to make decisions in his current state, he expressed his wishes clearly when he was well. Given that he has been involuntarily admitted, Reina is legally responsible for making medical decisions for Charlie, and she repeatedly asserts that she will not authorize treatment to which she does not think Charlie would consent if he were well, including antipsychotic medications. Reina is also aware, however, that not using at least a short course of medication makes managing Charlie's symptoms much more difficult for her, Laura, and the clinicians trying to care for him as best they can.

On the adult inpatient psychiatric unit, Charlie frequently acts out in response to his delusions, yells at staff members, and refuses to eat most of his meals because he fears the food is poisoned. During his stay he has repeatedly disrupted group therapy sessions with his outbursts. One of his dedicated nurses, Sheni, is becoming increasingly frustrated. She approaches the attending psychiatrist, Dr. Naobi, with her concerns, saying, "I don't think that it's fair to Charlie or the other patients on the unit if we are not going to manage his symptoms appropriately. How can we treat him with compassion and respect if we don't treat the symptoms from which he's suffering so acutely? It's just not good care to let his symptoms go untreated, and the other patients are suffering because we have to spend so much time managing Charlie's symptoms."

Dr. Naobi agrees that another family meeting would be worthwhile to try to address these concerns. During that meeting, Sheni describes in detail the severity of Charlie's symptoms and the effects those symptoms have on her, her colleagues, and other patients. After hearing Sheni speak, Laura confronts her mother, insisting that she authorize medications. Reina, however, is adamant in her refusal, saying, "He has told me time and time again what he wants. We are his best advocates. I know it's hard on everyone, and I regret that, but I must follow his wishes." Dr. Naobi also expresses concerns that allowing Charlie to suffer by continuing the current course of action is clinically and ethically inappropriate. "We've tried this for two weeks and it's just not working," he says. "From a clinical standpoint, many would just regard our current approach as medical mismanagement, as harmful and substandard care." Reina becomes angry upon hearing this and replies, "You don't know Charlie as well as I do. I remember how much he suffered due to those medications. Yes, they controlled his symptoms, but they also made him fat and left him feeling sluggish all the time. We talked about it for a long time before we decided that he wasn't going to take them anymore. It wasn't a decision that we made lightly, and I am not going to betray his trust in me because managing his illness is inconvenient for you."

Dr. Naobi feels very conflicted, but he manages to respond calmly. He continues, "I also believe that Charlie's wishes deserve respect. Let's end this meeting on that common ground and take another day to think this over together." Dr. Naobi knows that Reina has legal authority to make treatment decisions for Charlie, but he suspects that perhaps the scope of her influence has now entered the realm of medical management, which ought to be the clinician's prerogative. He wonders how best to communicate this concern to Reina. He also wonders about what the best strategies might be for acting in solidarity with Sheni and his other nurse colleagues.

Commentary

Before discussing the clinical and ethical issues raised by Charlie's current situation, we should reflect on the important distinction between *preventive* ethics (i.e., anticipating and preventing ethical problems before they arise) and *reactive* ethics (i.e., dealing with ethical problems after they surface) [1, 2]. With Charlie's experiencing the recurrence of a severe episode of paranoid psychosis, the ethical problems in his care have hit the fan, posing difficult questions for Reina, Laura, and the clinical team. They must *react*. But if the right kind of discussion, which is recommended in what follows, had taken place when Charlie discontinued antipsychotic medication two years ago, the ethical complexities Charlie's care poses now might have been prevented.

Planning for the Possibility of Psychosis Recurrence

The case scenario tells us that Charlie discontinued medication "in close collaboration with his psychiatrist." Nothing is said, however, about discussion of contingency plans with Charlie and his family for what to do if a relapse were to occur. Although Charlie's psychiatrist would want to approach the discontinuation of medication in an optimistic manner, the nature of schizophrenia is such that the potential for a recurrence of psychosis is real and should be planned for [3]. The psychiatrist must find a way to combine recognition of Charlie's strengths, respect and support for his very understandable wish to stop taking antipsychotic medication, and encouragement of hope with recognition of the possibility of relapse. Doing this isn't easy, but it can be done. Here's the essence of what the psychiatrist might say:

> *Charlie, it's been great to see how well things have been going for the last eight years! Taking the medication despite the miserable side effects has required a lot of strength on your part. Tapering and stopping it is an excellent step for us to take. I feel very optimistic about the future, and I'm happy about what we're doing. But we know that episodes like the ones you've experienced years ago can recur. Let's talk about how we should handle things if the paranoia came back…*

The process that should have happened has been much discussed as a "Ulysses contract" or, more formally, as a psychiatric advance directive [4]. The reference to

Ulysses in Homer's epic poem *The Odyssey* is this: Ulysses knew that the Siren's singing could lure sailors to their death, but he wanted to hear their enchanting song. He solved the dilemma by having his crew put wax in their ears, tie him to the mast, and not release him under any circumstances until the ship was past the danger. On hearing the song he temporarily lost his reason and begged to be untied, but since the crew could not hear his pleading or the Sirens they followed his orders, and the ship sailed to safety. As the story goes, Ulysses was saved from a foreseeable loss of reason by planning ahead.

It is worth noting that Charlie's psychiatrist need not ask Charlie to sign a formal document. What is important is to discuss with Charlie his values and goals of care as well as contingency planning should his psychotic symptoms recur. Such discussions are also fundamental to end-of-life care planning.

Clinicians might fear that raising "what if" questions about how best to handle a potential relapse might alienate or discourage patients. Evidence, however, suggests the opposite—that the process of exploring a patient's values with regard to future treatment can strengthen the alliance between patients, families, and clinicians [5]. In light of these findings, Virginia has undertaken a statewide effort to incorporate completion of a psychiatric advance directive into routine care for persons with serious mental illness in the public mental health system [6]. Unfortunately, Charlie does not appear to have received this kind of anticipatory planning, with the result that Reina, Laura, and the clinical team are now faced with difficult ethical questions that potentially could have been prevented. If Charlie, Reina, and Laura had discussed "how we should handle things if the paranoia came back," as suggested above, Charlie might have endorsed restarting medication, with the result that Reina might not have felt that she was betraying him if she agreed to using antipsychotic medication.

Dealing Ethically with Conflict Once Psychosis Recurs

In Charlie's current state of decisional incompetence, Reina is his proxy decision maker. She tells us that Charlie "has told me time and time again what he wants"—namely, to avoid all medication treatment in the future. On medication Charlie experienced weight gain and what sounds from the case scenario like type II diabetes. When he came off medication, these side effects improved and he felt much better. In addition to the fact that Charlie has a *right* to refuse treatment (directly or via his proxy), he has a strong, readily understandable *rationale* for his preference. Reina feels duty-bound to follow his wishes.

The case tells us that when Reina refuses medication for Charlie, Dr. Naobi "suspects" that she has "entered the realm of medical management, which ought to be the clinician's prerogative." His suspicion is incorrect. The right of a decisionally competent patient—or, in a situation like Charlie's, his proxy—to refuse treatment is well

established. Even though Reina's stance goes against what the team sees as good care, she is ethically justified in following what she takes to be Charlie's wishes.

But did Charlie's statements really mean that there were no circumstances whatsoever in which he would accept antipsychotic medication? That's how Reina interprets his wishes, and that's why she continues to refuse to allow him to receive antipsychotic medication. Her interpretation, however, may not be correct. Here's how Dr. Naobi and the nurse, Sheni, could raise a question about Charlie's real intentions at the meeting with Reina tomorrow:

> *Reina, we all understand why Charlie spoke so strongly against medication. It made him fat and gave him diabetes, and he felt much better when he stopped. If I had his experience, I wouldn't want to take medication, either. We've tried to follow his wishes and help him get better without medication, but it isn't working. Here's the question I've been thinking about: If Charlie had imagined getting so paranoid that he would attack Laura, would he have taken such an absolute position about medication? From what you and Laura have said about him as a loving father and husband, my guess is that he'd be open to using medication in the lowest possible dose so that we could get the paranoia under control and make it safe for him to return home. What do you think?*

Dr. Naobi could point out that, in the area of planning for end-of-life care planning, it's not unusual for people to make global statements like "I never want to be kept alive on a machine," because they have in mind the image of a frail person with dementia who will never recover cognitive capacity "vegetating" on a ventilator. If at a later time that person is otherwise healthy but develops severe pneumonia that will be fatal without short-term use of a ventilator—and is likely to return to full health if the ventilator is used—would we be bound by the emotional statement about not living on a machine? People sometimes speak in terms of specific interventions when their real intention is to convey underlying values and goals. If a person who says, "I never want to be kept alive on a machine," is asked, "would you object to using a ventilator for a couple of days if you had a pneumonia you would completely recover from?," that person might give more nuanced guidance, such as "I really meant that if my condition won't improve, I don't want to vegetate on a machine…"

My guess is that this is Charlie's situation, since he had good reason to hate taking antipsychotic medication and he expressed that attitude vehemently. The challenge for Reina and the team is to decide if Charlie meant those statements literally and absolutely, or if he was expressing something more like "I hate taking medication, so if a situation like what happened years ago happened again, I'd want to use the medication least likely to cause bad side effects at the lowest effective dose…"

If Reina concludes that this is what Charlie really meant, she will authorize use of antipsychotic medication. But suppose she doesn't. What then?

In the United States, we're devoted to individual autonomy. We accord supreme value to the right of persons to make their own decisions about health care. But as John Donne wrote almost four hundred years ago: "No man is an island, entire of itself; every man is a piece of the continent, a part of the main" [7]. State laws typically allow involuntary commitment of persons who are dangerous to themselves or others because of mental illness [8]. Thus even if Charlie had said, "I never want to be hospitalized ever again," when his paranoia created danger for Laura, his directive could be overridden.

But what about Reina's refusing to have Charlie medicated now that he is hospitalized? Law on this question is unsettled [9], but from the perspective of ethics, Dr. Naobi and the hospital can reasonably challenge Charlie's wish to avoid medication. His wishes deserve respect, but they do not necessarily trump respect for the other patients, staff, and his daughter Laura, who are put at risk by his paranoia. And if medication refusal resulted in an otherwise avoidable hospitalization that might last for months, it is reasonable to ask whether patients like Charlie have the right to commandeer funds from public or private insurance to satisfy their wish to avoid medication [10].

The case tells us that Dr. Naobi "feels very conflicted, but he manages to respond calmly," and that he ends the contentious meeting with Reina with a recommendation that they seek to find "common ground and take another day to think this over together." Conflicts about ethics typically evoke strong emotions, and Dr. Naobi shows excellent judgment in recognizing his agitation, calming himself, and proposing further deliberation and a cooling-off period. Overriding Charlie's advance directive should be avoided if possible and chosen only as a last resort. But if his clinical condition continues to pose a significant risk of injury to others despite the best possible treatment that does not include medication, after appropriate consultation with an ethics committee and legal counsel, antipsychotic medication should be given.

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