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Résumé de l'article

Un adénocarcinome endométrioïde de grade 1 a été diagnostiqué chez une femme ménopausée de 56 ans (FB), qui refusait une hystérectomie. La patiente comprenait qu’elle avait un cancer et qu’un traitement était nécessaire pour soigner sa maladie. Cependant, en raison d’un délire de grossesse bien ancré associé à un diagnostic de schizophrénie, FB pensait que l’intervention chirurgicale recommandée par son gynécologue nuirait au foetus qu’elle croyait en train de se développer dans son utérus. FB a été jugée incapable de consentir à une intervention chirurgicale en raison de son délire de grossesse, ce qui signifie que l’intervention pouvait être pratiquée avec le consentement d’un mandataire spécial. Dans ce texte, nous décrivons l’approche de notre équipe face au dilemme moral présenté, qui consiste à choisir entre imposer une intervention chirurgicale à une patiente réticente ou la laisser mourir d’une maladie traitable.

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ÉTUDE DE CAS / CASE STUDY

# "Not Until the Baby Arrives": When Delusional Pregnancy Impacts the Management of Uterine Cancer

Marnina Norys[a,b], Michael Szego[c,d], Eliane Shore[e], Julie Maggi[f]

**Résumé**
Un adénocarcinome endométrioïde de grade 1 a été diagnostiqué chez une femme ménopausée de 56 ans (FB), qui refusait une hystérectomie. La patiente comprenait qu'elle avait un cancer et qu'un traitement était nécessaire pour soigner sa maladie. Cependant, en raison d'un délire de grossesse bien ancré associé à un diagnostic de schizophrénie, FB pensait que l'intervention chirurgicale recommandée par son gynécologue nuirait au fœtus qu'elle croyait en train de se développer dans son utérus. FB a été jugée incapable de consentir à une intervention chirurgicale en raison de son délire de grossesse, ce qui signifie que l'intervention pouvait être pratiquée avec le consentement d'un mandataire spécial. Dans ce texte, nous décrivons l'approche de notre équipe face au dilemme moral présenté, qui consiste à choisir entre imposer une intervention chirurgicale à une patiente réticente ou la laisser mourir d'une maladie traitable.

**Mots-clés**
délire de grossesse, psychiatrie, consentement éclairé, capacité, oncologie, collaboration interdisciplinaire

**Abstract**
A 56-year-old postmenopausal woman (FB) was diagnosed with Grade 1 endometrioid adenocarcinoma but was refusing a hysterectomy. The patient understood she had cancer and understood treatment was required to treat the condition. However, due to a well-entrenched delusion of pregnancy associated with a diagnosis of schizophrenia, FB believed the surgery recommended by her gynecologist would harm the fetus she believed to be developing inside her womb. FB was deemed incapable of consenting to surgery due to her pregnancy delusion, which meant that the procedure could be performed with consent from a substitute decision maker (SDM). In this paper, we describe our team's approach to the presenting moral dilemma consisting of a choice between forcing surgery on an unwilling patient or allowing her to die of a treatable illness.

**Keywords**
delusion of pregnancy, psychiatry, informed consent, capacity, oncology, interdisciplinary collaboration

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## CASE[1]

FB was diagnosed with grade 1 uterine cancer and, according to the patient's gynecologist, a hysterectomy represented the standard of care. The complicating factor in this case was the fact that FB had a longstanding delusion of pregnancy associated with schizophrenia. Delusional pregnancy involves a fixed and often unshakeable belief that one is pregnant absent obvious signs that one is carrying a fetus (1).

When offered a hysterectomy, the patient stated she wished to wait until her baby's birth before undergoing the procedure. Although FB's gynecologist knew such a wait would be indefinite, the patient was amenable to medical management of the disease in the meantime. However, while medical management might slow the progression of the cancer, inevitably the disease would spread to neighbouring organs such that a frontline treatment such as a hysterectomy would become futile. Without the hysterectomy, her oncologist predicted FB had perhaps 5 years to live. Thus, the gynecologist proposed close monitoring of the disease progression via serial ultrasounds, MRIs and endometrial biopsies every 3 months. After a year of adhering to this plan of treatment, the gynecologist was unsurprised to see the cancer failing to respond to medical management. She struggled with the decision of whether to pursue surgery, since it was becoming clear this was the only remaining option that would save FB's life. Unsure how to proceed, the gynecologist contacted her hospital's ethicist in order to determine whether the patient was capable of giving an informed refusal and to workshop some potential alternatives to the status quo.

In Ontario, where this case occurred, the Health Care Consent Act (HCCA) defines "capacity" as a patient's ability to understand information about a proposed treatment and their ability to appreciate the consequences of either accepting or refusing that treatment (2). Capacity, moreover, is time and treatment specific, meaning that at any given time and for any particular treatment, patients must be able to meet both these thresholds to be deemed capable of consenting to or refusing said treatment. Although FB was relatively high functioning and consenting to her own psychiatric treatment, she failed the second branch of the aforementioned capacity test with respect to a hysterectomy and was hence deemed incapable of

[1] Consent to discuss details of this case was obtained from the patient and the authors received REB approval for this case study.


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consenting to this intervention. FB indicated that she understood her diagnosis of uterine cancer and that removing her uterus was her best chance of eliminating the disease. However, when it came to appreciating the consequences of accepting or refusing treatment, the guaranteed death of a non-existent fetus was a risk that trumped any other consideration. Furthermore, in her mind the delay was time limited and not indefinite. Hence, FB's delusion of pregnancy rendered her incapable of conducting a rational analysis of the risks and benefits associated with the proposed treatment.

## THE DILEMMA

If a patient is found incapable with respect to an offer of treatment, the HCCA requires substitute consent for offers of treatment in all non-emergent cases. Although the procedure was necessary to save the patient's life, FB's gynecologist had to weigh survival against potentially traumatizing her patient. Although the patient was not capable of an informed refusal, proceeding against her wishes could still be experienced as a violation of her bodily integrity. Not only might this undermine the patient's psychological wellbeing, but it could also erode trust in healthcare professionals. Any breakdown in the therapeutic alliance, moreover, stood to jeopardize immediate post-operative care as well as future medical interventions, including psychiatric care. It was also possible that an intrinsic component of FB's sense of identity was tied to being a pregnant woman, thus it was difficult to predict the consequences that might occur if removing her uterus shattered this perception of herself.

## THE PLAN

An inter-professional team was quickly formed that included the gynecologist, the patient's family physician, ethicists, and members of the hospital's inpatient and outpatient psychiatric services. Given the possible harms associated with forcing surgery on FB, the consensus was that this option only be considered as a last resort. The team therefore developed a careful, stepwise approach that started with a plan to eliminate the patient's delusion of pregnancy and thereby restore her decisional capacity. Given that her refusal of surgery was putting her life at risk, and a psychiatric illness gave rise to this refusal, FB met the criteria for an involuntary psychiatric admission. In Ontario, patients can be admitted involuntarily if, due to a psychiatric disorder, they pose a serious risk of harm to themselves or others or if they are deemed not capable of caring for themselves. Patients are provided advice on their rights by an independent rights advisor and can appeal their admission (3). In this case, FB did not appeal her involuntary admission. Once hospitalized, cognitive-behavioural therapy for delusions was provided and a change of medication proposed in the hope that, with better treatment, FB would become capable of accepting or refusing the hysterectomy. FB, however, was resistant to the proposal to change her medications.

After a week on the psychiatric inpatient unit, FB met with interprofessional team members and to everyone's surprise agreed to surgery instead of accepting a change in her psychiatric medication. This led to the concern by some team members that the proposal to change her psychiatric medication had functioned as a coercive influence on the patient's change of heart. Team members carefully probed her reasons behind the decision and learned that she understood she had cancer and wanted the surgery so she could survive. She also indicated that she did not like the side effects of the medical therapies she'd been trying the past year and made no mention of the baby.

Whatever her motivations for the shift in view, the patient's explanation revealed to the team that she understood information about the treatment proposal and appreciated the consequences of accepting or refusing treatment. Her psychiatrist and gynecologist thus felt that she met the threshold for capacity, meaning she no longer met the criteria for involuntary admission and so the patient was discharged from the psychiatric unit.

## OUTCOME

Several days after she was discharged, FB voluntarily returned to hospital to undergo a hysterectomy, and the procedure and her postoperative course were uneventful; the final pathology confirmed the presence of uterine cancer. FB engaged in regular follow-up care for over a year, and during one such visit, she mentioned she was pregnant.

## CONCLUDING THOUGHTS

People with serious and persistent mental illness die approximately 15-20 years earlier than the general population and the majority of such premature deaths are due to physical illnesses rather than suicide (4). Such patients are also less likely to receive preventative screenings or interventions for cancer or cardiovascular disease compared to the general population (5-7). Although diminished help-seeking behaviour or lifestyle factors such as smoking may account for a percentage of premature deaths, the stigma associated with mental illness (8,9) is also likely a contributing factor. Not only may physical symptoms be dismissed as symptoms of mental illness in stigmatized patients, but health care providers' own biases towards people with severe and persistent mental illness may undermine the development of therapeutic relationships required to sustain complex and protracted plans of treatment. Such health disparities further complicate already complex ethical deliberations in cases where patients with a mental illness refuse lifesaving medical treatment, and they oblige health professionals to take extra measures in order to avoid perpetuating existing injustices by abandoning patients prematurely. A careful, thoughtful approach to patient care aimed at winning patients' cooperation may help avoid having to make the terrible choice between forcing invasive medical procedures on incapable patients, or simply leaving them to die a preventable death.

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