

# John Has Hepatitis and Schizophrenia

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## John's History:

John is a 52 year old man who is currently hospitalized with a diagnosis of schizophrenia and hepatitis caused by chronic infection with hepatitis C virus. He has a hepatic encephalopathy that is partially controlled with lactulose which lowers ammonia levels in his blood, but does not affect the progression of his hepatitis. His schizophrenic symptoms have been resistant to treatment by a variety of anti-psychotic medications alone and in combination, including clozapine. Despite treatment he remains delusional believing that he is extremely wealthy, and that he does not have either liver disease or mental illness. He does not appear to experience distress as a result of these delusions, although is angry and upset that he is held in a psychiatric facility against his will. He denies symptoms of depression or anxiety and does not demonstrate significant agitation.

Under the legal framework within which he currently resides and receives treatment, he is hospitalized involuntarily, and has been for a long time in order to prevent substantial mental or physical deterioration, as he is unlikely to follow the treatment plan necessary to minimize the possibility that he will require re-admission. In this jurisdiction, as he is admitted involuntarily under the mental health act, and as he is deemed incompetent to consent with respect to his psychiatric treatment, he can receive psychiatric treatment against his will at the decision of his treating team, but not medical care. He does not have contact with any family members at all, being completely estranged from his siblings, and having never married or had children. Application for consent for medical care can be made to the public guardian who can provide substitute decision making and consent for his medical treatment.

Currently, his liver disease is progressing and it is estimated that, untreated, he will die of liver failure within 2-5 years. Treatment with interferon and ribavirin has a substantial chance of slowing the progression of his hepatitis, and even eradicating the infection and hence arresting the progression of his illness, although it would not improve his liver function from its current level. It remains likely given his stage of progression of liver failure that he will nonetheless die of this, but treatment could significantly prolong his life. Improvement of his psychiatric symptoms could arise either as a result of some improvement in his hepatic encephalopathy, or in liver function that would allow then more aggressive treatment of his symptoms with medication, previously limited by the fact that many anti-psychotics are metabolized by the liver and hence

toxicity can develop in people with liver illness. This is unlikely though as treatment at its best usually only stabilizes liver function, although some resolution of acute infection could result in a modest improvement in liver function.

Standard treatment with interferon and ribavirin for hepatitis C, depending on viral genotype, is generally 48 weeks requiring daily medication and weekly injections. There is a significant risk of worsening of John's psychotic symptoms during the treatment, as well as other mental and physical side effects including depression, anxiety and irritability, insomnia, myalgia (muscle pain), rash, arthralgia (joint pain), nausea, vomiting, anorexia and flu like symptoms such as rigors (shaking chills). These are not easy medications to take. Given that his psychotic symptoms even now can only be partially controlled, exacerbation of these symptoms could be significant and quite disturbing to John.

At this point, providing treatment would be contrary to his currently expressed refusal to accept any such medical treatment on the grounds that he believes he does not have hepatitis, as a result of his psychiatric illness and consequent delusions. We have no evidence to indicate what his wishes would have been when he was well and able to consider the options. Treatment would expose him to significant side effects that could cause marked distress and discomfort, which could be alleviated only by stopping his anti-viral treatment although other measures would be tried before that. In the end the ultimate outcome would not be changed, as he would still likely die as a result of his liver illness. His psychiatric illness is likely to remain unchanged regardless of the success of his liver treatment, and so he may continue to require psychiatric hospitalization or care in a secure environment in the community for many years, limiting his freedom. At the same time, failing to provide the treatment on the basis of not having previously expressed wishes one way or the other, and the lack of capacity to consent, would mean that he will die sooner than otherwise of his liver failure, and it could be seen as providing less than optimal care of his medical illness on the basis only of his also having a mental illness, which would be a form of discrimination.

\* Brief commentaries in response to this case were written at the invitation of the editors of JEMH.

## 1. Joint Commentary on “John” by:

**Stephen A. Green MD**

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**Sidney Bloch MB PhD**

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One could not encounter a more tragic situation than that of John, a middle-aged man afflicted by two horrific illnesses, compounded by the fact that each is resistant to treatment.

We are often tempted to view patients with severe chronic mental illness and physical co-morbidity differently from those who are only affected by the latter, namely, that it is not as worthwhile treating a physical condition in an individual like John as is the case in treating someone not suffering from an intractable mental illness. Such a view is tantamount to discrimination and a violation of a basic right to “good enough” health care. Our first caveat, therefore, is that John not be treated dissimilarly to any other patient with a progressive physical disease.

How then should we proceed to treat him? Given that his loss of insight is both complete and likely to endure, and that we have no indication of his previous preferences in any dimension of his life, we have no option but to adopt the principle of beneficence; attempting to identify any residual sphere of autonomy seems utterly futile.

In acting paternalistically we face the awesome task of trying to ascertain both what are likely to be in John’s best interests and what he himself would perceive in that regard. As we are so often reminded, the first value here is *primum non nocere*—not to cause him harm. This is easier said than done in that any decision taken regarding his health care will have profound repercussions for his overall quality of life. Moreover, we are hamstrung in not being able to determine the medical decisions that would promote John’s best interests. For example, we have little idea of the potential adverse effects of the treatment for his hepatitis, nor how John would wish to deal with them. On the other hand we do know that the effects of both his illnesses and the interferon treatment for his hepatitis will severely diminish his quality of life. We therefore face the uncomfortable conclusion that we have no choice but to assume responsibility for his fate; specifically, our line of reasoning supports not treating his physical illness.

Our position has revolved primarily around principle-based ethics, but we should not lose sight of the potential role of care ethics. We mean by this paying attention to the contribution mental health professionals are obliged to make in being empathically attuned to John’s needs as a human being for sensi-

tive and compassionate care. (1) As Annette Baier (2) has so poignantly expressed it, “There but for the grace of God go I”.

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## 2. Commentary on “John” by:

**Walter Glannon, PhD**

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Because John lacks decisional capacity due to his psychiatric illness, he can be given antipsychotic medication against his will. What complicates this case is that legally he cannot be forced to take treatment for his liver disease, even though he has been deemed incompetent and treatment for this condition is medically indicated. His hepatic encephalopathy may exacerbate his psychiatric symptoms and treating his hepatitis C might alleviate these symptoms. The efficacy of treatment would depend on the viral genotype. If it is likely to be effective, then John’s physicians have at least a prima facie obligation to prevent harm to and benefit him by treating both diseases. This would be consistent with the medical ethical principles of nonmaleficence and beneficence, though it would mean overriding John’s expressed refusal of treatment. Yet it is not an autonomous refusal given his delusional state. John’s health care providers have a professional duty to act in John’s best interests, and he does not know what is in his best interests, or the consequences of not treating his hepatitis C. Treating his liver disease would appear to violate his freedom from interference with his body. But treatment could free him from the pain and suffering caused by the combination of his two conditions.

Still, treating John against his wishes can be ethically justified only if: (1) his delusional state completely undermines his decisional capacity; and (2) his medical conditions entail a significant risk of harm to him. The fact that John does not believe he has liver disease or mental illness indicates that he lacks decisional capacity. Moreover, the likelihood of a shorter life span from hepatitis C and a worsening of his psychiatric symptoms constitute a significant risk of harm to him. For these reasons, treating John for both medical conditions can be ethically justified. With respect to benefit, therapeutic intervention can be justified not only with a view to increasing the quantity of his life years, but also to improving his quality of life. For both quantitative and qualitative reasons, treating both psychiatric and hepatic conditions can prevent harm to and benefit an incompetent patient.

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# ANALYSIS

## Actual Case Outcome

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Upon review of the opinions provided with respect to John's care, the treatment team was left with a decision to make regarding next steps. We did apply to the Public Guardian who is legally empowered in our province to provide substitute decision making for individuals such as John who are unable to provide consent, and who do not have alternate SDMs available (John is completely estranged from his family). The Public Guardian did provide substitute consent for hepatitis treatment.

Following the reasoning provided in support of treatment under the principle of beneficence, we then addressed the practical issue of treatment. In the case of treatment with ribavirin and interferon, administration requires both daily oral capsules and weekly intramuscular injections. For the medication to be effective, they need to be received at least 80% of the time. John is extremely resistant to taking medications, especially oral medications. He is able to detect any attempt to provide medication in food or other liquids and will refuse anything he detects as altered in any way. This extends to medications of all kinds, whether for comfort, minor medical problems or psychiatric medications. He is more accepting of injections as long as they are infrequent and so his psychiatric medications are provided now by depot intra-muscular agents. This step has improved his quality of life in that he avoids daily struggles with nurses trying to convince him to take medication and he has both a greater sense of freedom and autonomy as a result, as well as being able to avoid experiences of conflict and argument. Thus despite the fact that we had substitute consent, we felt that the lack of sufficient assent by John was such a barrier to being able to provide effective hepatitis treatment that we would not proceed with such treatment. Should John's experience of his illness change, such that he is more willing to assent to oral medications, we would then be prepared to address this issue again.

The opinions provided illustrate the difficult balancing act that clinical teams need to perform in trying to balance principles that are often in conflict. With the difficulty inherent in providing this particular treatment for this particular individual, we felt that the balance between beneficence and primum non nocere was further tipped to the side of not causing harm, as forced oral treatment would be so destructive to the therapeutic environment in which John has to continue to live and would be so prolonged (often up to 48 weeks) that it would have a significantly negative impact on his quality of life as well as reducing significantly the likelihood of efficacy of the treatment for his

hepatitis due to problems in ensuring sufficient medication actually enters his system to be effective. Although it is impossible to know what decision John would make were he able to provide informed consent, his resolute refusal of any and all oral medications, regardless of indication, and the improvement we have seen in his overall sense of well being and comfort when we stopped other oral medications provide us with a sense at least that the decision we are making for John, even if forced by practical issues of medication delivery, may in fact be consistent with what he would have wished even if he were able to more clearly appreciate his current situation.

So in the end, one might ask if an ethical consultation was of any use, if we are just in fact choosing the answer we would have chosen any way. Ethical decision making is never free of bias in the decision maker but, at least by analyzing the principles involved, we can be more conscious of the full range of the issues underlying any clinical decision. Having opinions available that conflict is helpful for clinicians at least to ensure that we have fully reflected on a difficult decision and to provide assurance that the discomfort we may feel in making those decisions is honestly derived.

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