Where Ethics Comes from and What to Do about It

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CASE STUDIES

The Transplant Baby from Outer Space

The issue of marginal capacity portrayed in this case puts society on the horns of a dilemma. Unless society allows physicians a relatively free hand in treating patients at the margins of competency, these patients may not receive therapies they need without delay or encumbrance. The cost here is measured in terms of the health, perhaps life, of the patient. On the other hand, allowing physicians such freedom strips patients of their right to refuse treatment. The cost here is measured in terms of patient autonomy and dignity.

As a civil libertarian (former head of the British Civil Liberties Union), I believe that recognition of a patient's right to autonomy and self-determination is critically important to preserve her dignity. But, as former head of the National Association for Mental Health in Great Britain, I also believe it does not always serve the person's interests to allow her to refuse treat-

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COMMENTARY

by Richard T. Hull

This is a case in which the behaviors of the patient needed interpretation as much as her symptoms needed diagnosis and treatment.

First, it is evident that there was never a question of whether to perform the surgery or select an alternative treatment more in keeping with the patient's expressed wishes. Had the patient been prepared to agree to surgery, the question of her competence to authorize it would not have been raised. It was her refusal of surgery that initiated a search for "other" evidence of incompetence, and the discovery of previous diagnosis of schizophrenia "permitted" Dr. S to declare her incompetent and seek the court order.

The confirmation of incompetence to consent found in the patient's delusional postoperative state is another disturbing aspect of this case. Many patients, otherwise normal in mentality, who enter a hospital for surgical treatment experience what has earned its own name—hospital psychosis. We see no attempt to distinguish between that possible diagnosis and the diagnosis of underlying, persistent schizophrenia of a degree that would render the patient wholly incapable of a valid consent. Evidence obtained post hoc and used to justify a decision before surgery to deprive a patient of her autonomy smacks of a kind of opportunism.

Her remark about obtaining her father's permission cries for interpretation, yet seems to have been ignored. This remark was made before incompetence was declared, and so should have been viewed as either a request for the counsel of a trusted family member or as designating a proxy decisionmaker. Even when the history of involuntary associations with hospitals and physicians was discovered, the fact of her voluntarily seeking medical help despite a strong aversion to hospitals and physicians, together with a reasonable interpretation of her remark about her father's permission, should have been grounds for respecting her particular way of making decisions instead of circumventing it.

Her attempt to choose an alternative therapy, based on her past experiences, does not seem to have been seriously explored with the patient or to have been considered by the medical staff. Dr. S's dismissal of her request to be treated medically rather than surgically, finessed through the "finding" of incompetence, renders moot Ms. M's own experience with her medical history, her own wishes, her own wisdom as to the events transpiring in her own body.

Could not a bargain—and a useful one—have been struck by agreeing to start Ms. M on a nonsurgical course of treatment with antibiotics and ice packs, closely monitoring her symptoms and signs, provided that she would seriously consider surgery? In that way the long hours of waiting for legal clearance could have been put to good use, according this patient the dignity of treatment that she was prepared to accept and perhaps thereby strengthening her trust and confidence in the medical team. Instead, we are left with a patient whose intermittent autonomy is further undermined and whose trust in her ability ever to exercise it authoritatively in a medical setting has once more been betrayed.

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