case study

Devotion or Disease?

V, a fifty-year-old woman, called 911 for help. Police arrived after her husband refused entrance to the paramedics who responded. Once police gained access to the house, they found MV in the bedroom. She fluctuated in her ability to communicate. Her husband would not give them her identification, and the police suspected abuse. A suitcase was on the bed, and police asked MV if she was trying to leave her husband. She could not answer. They decided to send her to the emergency room because she was emaciated and intermittently mute.

MV's medical records indicate that she has schizophrenia. She was admitted

to the hospital ten years ago for a similar episode. Her husband confirms that she had recently been treated with vitamins by her family doctor in accordance with the couple's beliefs in Scientology. MV is admitted to the psychiatry unit as an involuntary patient and deemed incapable of consenting to treatment. She has no advance directive or living will.

Early in the course of her treatment, her doctors note that MV is delusional. Much of what she says is incoherent, so they look to her family for help. Her sister tells the health care team about the family's strong history of schizophrenia. She says that MV has never accepted her diagnosis nor believed that she needs treatment. She also explains to them that MV became a devout Scientologist

when she met and married her husband, and that this occurred right around the time she was first diagnosed.

MV slowly begins to improve, but she shows no insight into the nature of her psychiatric illness. She is adamant that she does not need antipsychotics and that such treatment could never benefit anyone. This conviction is reinforced by Scientology, and she refuses further treatment on grounds that it would be inconsistent with her religious beliefs. Based on these statements, MV's psychiatrist thinks her patient remains incapable of making her own health care decisions. But because MV is no longer malnourished or dehydrated, her potential to harm herself is greatly diminished, and she can no longer be kept against her will.

Her treatment team encourages MV to weigh all her treatment options, but MV does not acknowledge having any psychiatric problem. The only problem that she will acknowledge is that her husband is abusive: she says he attempted to smother her with a pillow. She will not press charges against him, but she does intend to separate from him. She says she called 911 for help with her domestic abuse, not for medical assistance.

Should MV's health care team respect her treatment refusal?

commentary

by Catherine Hickey

It behooves us to examine the role religion plays in decision-making ability. It especially behooves us to examine how religion impacts decision-making ability in vulnerable patients.

MV is such a vulnerable patient. She struggles with a psychiatric illness she does not believe she has. She struggles in a marriage that she later admits is abusive. She wants to be an autonomous and independent woman. Her involvement in Scientology may have reflected

her desire to autonomously choose a faith that reflected her belief system. Or perhaps, given her vulnerability, she was subtly coerced into her faith by her husband years ago.

Nonetheless, her vulnerability persists. Her family doctor mistreated her psychosis with vitamins, and she deteriorated. Her husband did not cooperate with authorities and was later disclosed as an abusive man. MV arrives in the emergency room in an emaciated and catatonic state. But her call to 911 clearly indicated that she was requesting help.

Despite the complexities of the case, there are several incontrovertible facts. MV is at risk of dying if she returns to her home and continues to get treatment in the community from her family doctor. The decision to enforce hospitalization by making her an involuntary patient is an easy one. She has a documented psychiatric illness and is at risk of death without inpatient treatment. The treatment team likely has one main goal—to provide hydration and nourishment so that she does not die.

When she recovers and becomes more communicative, there will be new and challenging ethical considerations. Vulnerable patients need advocacy, and MV is no exception. Her husband and family doctor have failed to advocate appropriately for her, as evidenced by recent events.

The team has to examine what it means to be an advocate for this vulnerable patient. Some may argue that this woman has the right to pursue her religious beliefs and to refuse all treatment. However, MV has no insight in to her illness. This denial of illness is reinforced by her religious beliefs. Given that she does not recognize that she is ill, she can't possibly be capable of deciding to accept or refuse treatment for her illness. She remains vulnerable and at risk. She should be declared incapable of making treatment decisions, and a

substitute decision-maker should consent to (or refuse) treatment. Her sister might be a candidate for this role.

There are instances where religious beliefs can negatively impact a patient's decision-making capability. This is such a case. MV was physically and emotionally frail on admission to the hospital. Psychiatric treatment made her healthier, to the point that she can now communicate and express her wishes. Without such treatment, she likely would have remained extremely ill or died.

Any belief system that categorically prohibits psychiatric treatment in all cases is dangerous. Respecting MV's wishes early on in her admission would have resulted in clear harm to her. She

would have remained catatonic and psychotic. Hydration and feeding would not have been possible. The treatment team would be faced with a decision: to either continue with involuntary admission and watch MV slowly perish, or to discharge her to the home environment that led to her frail and emaciated state. Neither alternative is in the best interest of this vulnerable patient.

Religious beliefs can strongly influence a patient's ability to make decisions for herself. In this case, MV's religion tells her that psychiatric treatment is wrong in all cases. With such a belief system firmly in place, I doubt that she can ever make a truly well-informed decision about her psychiatric health.

commentary

by Adrienne M. Martin

This case would be simpler—not simple, but simpler—if it were possible to disentangle MV's commitment to Scientology and her schizophrenia. If we were able to disentangle the two, it would be appropriate to seek answers to the following questions.

First, is MV refusing psychiatric treatment because she is psychologically incapable of understanding the nature of her illness? If she is, then she does indeed lack the *capacity* to make decisions regarding the treatment. But that does not determine whether we should treat her as *incompetent* to make this decision—in other words, whether we should treat her as if she has no right to self-determination in this arena.

To make that determination, we need to answer a second question: Is her commitment to Scientology or her schizophrenia the source of her failure to understand? If she cannot understand the nature of her illness because she is a devoted Scientologist, then we, as members of a liberal democracy committed to toleration and religious diversity, are also committed to permitting her to determine her own course of treatment, so long as she does not pose a serious

danger to herself or others. (It is important that her devotion does not itself arise from psychiatric disorder.) If, however, her delusional schizophrenia is the source of her decisional incapacity, then we should seriously consider seeking a surrogate decision-maker.

Unfortunately, the situation does not allow us to disentangle MV's commitment to Scientology and her schizophrenia in the way the second question requires. Given that she converted to Scientology and was diagnosed with schizophrenia around the same time, it is for all intents and purposes impossible to determine whether schizophrenia contributed to her conversion, and to what degree her schizophrenia and her commitment to Scientology depend on each other.

Thus, if we do conclude that she is incapable of understanding the nature of her illness, we cannot know whether the source of this incapacity is the sort of thing that requires tolerance and respect, such as a religious commitment, or the sort of thing that recommends a paternalistic approach, such as psychiatric illness. In such a situation we should consider what is at stake in granting or denying the patient the right to self-determination with regard to this treatment decision. Denying this right is a serious matter, particularly for someone in MV's situation: her abusive husband

is not an appropriate surrogate, and while her sister may have her best interests in mind, she has a very different set of values. More generally, MV is almost certain to feel deeply estranged from any assigned surrogate because he or she will be a person who rejects central tenets of MV's Scientology. It is difficult to imagine how MV could feel anything but captive to a hostile group if she is forced to undergo psychiatric treatment on the basis of a decision made by such a person.

Granting her the right to self-determination does involve some risks. This is, after all, the second time she has been hospitalized due to what appears to be either self-neglect or mistreatment by her husband. So there is a chance the situation could occur yet again. However, she has stated her intention to leave her husband, and this suggests a desire to care for herself and protect herself from harmful others. If her caregivers believe she does not pose any immediate danger to herself or others, it seems best to respect her decision to refuse treatment, even if that decision may ultimately stem from her psychiatric illness. This is especially true if they can get some assurance that her sister or another individual who does not share her commitment to Scientology will be keeping an eye out for her well-being.

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