Published in final edited form as:

Curr Psychiatry Rep. 2013 August ; 15(8): 380. doi:10.1007/s11920-013-0380-5.

Capacity, Confidentiality and Consequences: Balancing Responsible Medical Care with Mental Health Law

Steven J. Siegel

Translational Neuroscience Program, Department of Psychiatry, University of Pennsylvania, Philadelphia, Pennsylvania; Bioengineering Graduate Group, University of Pennsylvania, Philadelphia, Pennsylvania siegels@mail.med.upenn.edu

Keywords

Mental health law; Schizophrenia; Organic brain disorders; Decision making; Safety; Psychiatry

The Health Insurance Portability and Accountability Act (HIPAA) is routinely cited as the reason physicians cannot share critical medical information about patients' condition, even when doing so could save the life of the patient or others. However, this is only one of the many factors that interfere with appropriate communication among all of people trying to help patients remain safe and well. The result of these various factors for families of people with schizophrenia is a devastating lack of ability to care for people, some of whom, realistically lack the capacity to care for themselves. The heart of the matter is that people with schizophrenia retain their right to make decisions, even when their illness may result in behaviors that are based on false beliefs, false sensory experiences and a fundamental lack of insight. Clinicians who treat schizophrenia patients are all too familiar with the daily experience of watching a patient discontinue care due to lack of insight, coupled with persistence or exacerbation of symptoms. Under these circumstances, the patient becomes increasingly disorganized, disconnected from society and in many cases dangerous. Worse yet, this cyclic pattern of disengagement, followed by deterioration, leading to hospitalization and recovery is often highly predictable. Yet, even under these circumstances, it is practically impossible to reach out and take benevolent control of the individual's choices until they have already demonstrated a clear and present danger. The same would not be true for any other form of medically-induced disruption of brain function. Rather, a patient with encephalitis or brain malignancy that alters their capacity to make rational decisions would be cared for by surrogate decisions makers until such time that they could responsibly make their own choices. The three cases noted below illustrate how this dichotomy between so-called "organic" brain disorders and schizophrenia should be abolished. A more civilized and humane system would require that physicians, family members and governing bodies provide benevolent intervention to care for symptomatic schizophrenia patients long before they either harm themselves or someone else. Each of the cases is true, although demographic details have been sufficiently altered to protect the privacy of the patients and their families.

Case Study 1: A 21 year old young woman was seen in consultation at the behest of her family. They described that their daughter had been popular in high school, but had become increasingly isolative and disengaged from friends over the past 1.5 years. She remained in her room, refusing to interact with anyone outside the family. However, she ate meals when prepared for her, bathed and was neither agitated nor aggressive to anyone at home. She had

Conflict of Interest Steven J. Siegel declares that he has no conflict of interest

seen a variety of psychiatric care providers while in high school, but refused to remain in care with anyone and had not seen a professional for more than 6 months due to her refusal. During the exam, she was cooperative and pleasant but lacked any insight into the gravity of her situation, stating only that she could handle whatever was happening. She appeared to be responding to hallucinations during the interview, and evaded all questions regarding delusional content. She also denied suicidal or homicidal thoughts. In short, she was highly symptomatic but not actively dangerous. She declined medication, as she had in the past, and left without making a follow up appointment. One week later she greeted her parents as they went to work, and then fatally stabbed herself through the heart. In retrospect, there were no committable behaviors as defined by current criteria. Alternatively, it was obvious to everyone that she was ill, lacked insight into her condition and was refusing the appropriate medical treatment that could restore a large degree of normal brain function.

Case Study 2: The patient is a 32 year old male with 12 year history of schizophrenia. He dropped out of college after his first break, and proceeded to live on the streets, in and out of jail for 7 of those years. He has persistent and constant auditory hallucinations and delusions, leading him to steal vehicles in the service of his perceived mission for the government, reporting that Bill Clinton sends him commands through satellites. He entered into care three years ago at the request of his parents. He was malodorous, isolated and unemployed. However, he agreed to visits and eventually accepted a monthly depot medication. While treated with the depot formulation he slowly improved to the point that he agreed to stay in an apartment provided by his parents, held a job, began playing sports with his peers and built better rapport with his parents. However, after 3 years of the most stable period in his adult life, he became convinced that the facility at which his physician worked was involved in a conspiracy against him and that he should not go to his appointments. Without his monthly injection he deteriorated, was lost to follow up and disengaged from his family. Ultimately, his behavior led to multiple involuntary commitments, the last of which was based on his unwillingness to come inside during a “code-blue” city-wide effort to shelter the homeless population. In short, he lacked the ability to choose his own home rather than freeze to death. He then spent 5 weeks in hospital, having thrown away three years of progress, and returning to the state of isolation and poor self-care in which he began treatment. He is now poised to rebuild his life, albeit with the caveat that he retains the ability to put himself in danger again by stopping his medication at any time.

Case Study 3: The patient is a 23 year old male who entered care through a prodromal outreach program. He reported an inability to feel anything, and a total lack of emotions or motivation. Although he had done well in high school, he chose not to pursue college. His only possible positive symptom was the persistent complaint that part of his body did not function properly. Results of his medical work up suggested that his perceived physical dysfunction could be a somatic delusion. The patient continued to experience negative symptoms, poor occupational function with increasingly odd social interactions. For example, he would insist that his physician take a piece of his brain to study, and would become visibly annoyed that no one was fixing his problem. This escalated from approaching staff at the clinic to report his doctor was not doing a good job, to a series of emails indicating that he was dissatisfied with his progress. Over the past 6 months his behavior became more chaotic with erratic behavior, missing appointments or showing up at random times when the clinic was closed, sending incoherent and inappropriate messages, to his physician, culminating in a suicide email. The police were notified and performed a wellness check at his residence, ultimately without locating the patient. He then proceeded to launch a barrage of sexually aggressive messages towards his physician, the other physicians and staff in the practice, eventually alluding to his doctor's family. After he tracked down his doctor's teenage daughter and sent her sexually explicit messages, the

police were engaged again to perform another wellness check. His grandmother declined to provide his current location and the police informed his physician that there was no committable behavior to justify further action. That is where the story ends for now, with a grossly psychotic, sexually aggressive individual whose delusions drive his desire to accost his physician and his physician's family. As with each of the previous cases, the fact that a patient's decisions are heavily influenced by a brain disorder, leading to psychosis and lack of insight, does not preclude their ability to act in a way that places themselves or others at grave risk.

This is the state of American Medicine, Psychiatry and society in 2013, where we continue to distinguish loss of brain function due to psychiatric disorders from all other organic brain disorders. Privacy and mental health laws, coupled with our historical valuing of individual rights, have created a situation that makes us frankly uncivilized in our care of people with major psychiatric illness. Generally this issue only comes to light briefly after a major catastrophe, like a mass shooting or high profile assassination attempt. Even then, the story passes in a week and the focus turns quickly away from the root causes of why the individual who committed the act was allowed to be in a position to cause such harm. It is time that physicians, other health care providers and mental health advocates take up the mission of bringing change for a more responsible and civil society. Leading professional and advocacy organizations, such as the American Psychiatric Association (APA) and National Association for Mental Illness (NAMI), could take specific actions including: 1) draft clear position papers advocating for early intervention based on symptomatic decline rather than demonstrated danger; 2) lobby federal, state and local lawmakers to reexamine mental health laws, and enable police and outreach workers to bring patients into an emergency room for evaluation without prior evidence of danger; 3) allow involuntary hospitalization and medication based on medical need and 4) support public campaigns to educate the greater public about the biological bases for mental illness and need to exert compassionate intervention before it is too late. In such a campaign, it will be important to note that individuals suffering from schizophrenia and other severe mental illnesses are more likely to be the victims of violence than to cause it, further emphasizing the need to step in early and provide benevolent care.

Virtually every medical student is indoctrinated with the words of Francis W. Peabody from his now famous 1925 lecture, "the secret of the care of the patient is in caring for the patient." This begins with caring for those who cannot take care of themselves. It's time we stop pretending that schizophrenia and other major psychiatric brain disorders are outside the purview of that collective responsibility.