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Legal, Ethical and Clinical Implications of Prescribing Involuntary, Life-Threatening Treatment: The Case of the Sunshine Kid

ABSTRACT: Involuntary treatment is a concept often familiar to psychiatrists. In clinical practice, it usually involves the hospitalization and pharmacological management of patients with severe mental disorders. However, the scope of involuntary treatment is not limited to the management of mental illness alone. Psychiatric patients afflicted with medical illnesses may require hospitalization and invasive procedures for optimal management of these disorders. The following case illustrates a dilemma in which a psychotic patient refuses life-saving medical treatment; however, the treatment itself carries significant risk of morbidity and mortality. This article reviews the ethical, legal and clinical implications of making such difficult treatment decisions.

KEYWORDS: forensic science, forensic psychiatry, involuntary treatment, capacity, competence, substitute decision making, patient autonomy, nonmaleficence

Involuntary treatment is a familiar concept to psychiatrists. In clinical practice, this usually involves the hospitalization and pharmacological management of patients with severe mental disorders. The scope of involuntary treatment is not limited to the management of mental illness alone. Psychiatric patients are commonly afflicted with medical illnesses as well and may require hospitalization and invasive procedures for optimal management of these disorders. In many instances, these patients lack the capacity to consent to or refuse medical treatment (1,2). In the state of New York, patients who are found to lack the capacity to decide their treatment may have a guardian, conservator, or committee consent to treatment on their behalf. In the case of "extraordinary care," such as sterilization, surgery, and electroconvulsive therapy (ECT), the decision is left solely to the court (3). What happens when the recommended treatment is potentially life threatening or is associated with substantial morbidity? This treatment, of course, would only be considered if the patient's untreated condition was equally as life-threatening. Nevertheless, this does not diminish the difficulty a clinician may face when prescribing life-threatening treatment to a patient against his/her will. The following case presentation illustrates such a dilemma and lays the groundwork for a discussion of the legal and ethical implications of involuntary treatment.

Case Presentation

At the time of hospital admission, the patient was a 62-year-old, never married, black woman, a retired nurse and resident of an adult home. She had worked for the local city hospital for several years until her abrupt "retirement" 30 years ago, which followed shortly after she was diagnosed with paranoid schizophrenia. Her caseworker brought her to the hospital for evaluation of increasingly disorganized behavior. Two weeks prior to admission, she developed a disabling cough and was referred to a pulmonologist for evaluation. She was found to have a right lower lobe (RLL) mass on chest X-ray and it was recommended that she undergo bronchoscopy with biopsy. The patient returned home and did not follow up with the recommended diagnostic procedure. According to her caseworker, she began to exhibit disorganized speech and thinking, often making inappropriate comments to her co-residents. Over the ensuing days she also developed slurred speech. An emergency evaluation was undertaken for a suspected stroke, but this was negative. The patient became progressively more disorganized and the caseworker brought her to the psychiatry emergency room for evaluation.

Past Psychiatric History

According to the patient and her family, she functioned well until her early thirties when she was hospitalized for a "mental breakdown." The details of her past treatment were unclear, but the patient reported that "many years ago" she was hospitalized and recalls receiving 19 ECT treatments. She was discharged to an adult residence where she has remained for almost 30 years. At baseline, she has bizarre delusions (e.g., she calls herself "The Sunshine Kid" because she "controls the sun and its radiation"), but has remained stable over the past ten years with little change in her delusions on antipsychotics. At the time of admission to the hospital, she was taking olanzapine 15 mg/day.

Medical History

The patient has multiple medical problems including poorly controlled insulin-dependent diabetes mellitus, hypertension, chronic obstructive pulmonary disease, and hypercholesterolemia.

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The patient had an 80 pack-year smoking history, but denied illicit drug or alcohol use.

Hospital Course

On the unit the patient identified with the staff and called herself "Nurse J" and "The Sunshine Kid." The staff accepted her behavior and developed strong positive feelings toward her. She wore her white nursing cap six days a week when she was "on duty" and a dressy black fur hat once a week when she was "off duty." When on duty, she would keep track of the patient census and try to help the other patients with nursing needs. At times, however, her behavior was intrusive and loud. She would walk around the unit singing disco songs off key and venture into the nursing station to assist the staff.

The treatment team quickly confirmed that her previous pulmonary evaluation revealed an enlarging RLL mass. The patient continued to deny that she had any medical illness. She was started on divalproex sodium and the dose was gradually increased to 1500 mg/day. Haloperidol 5 mg/day was also added to her daily 15 mg dose of olanzapine. She gradually became more organized and agreed to further evaluation, but continued to refuse bronchoscopy. Although she began to acknowledge the presence of the pulmonary mass, she would minimize its significance, claiming that as "The Sunshine Kid," her own radiation would heal her. The hope was that if medication could help her become less delusional, perhaps she would comply with the necessary tests, however, this did not come to pass. Her sisters met with the treatment team and agreed that she should receive the diagnostic tests and were willing to support the recommended treatment plan in court.

A pulmonary consultation was obtained to establish what tests the patient would need and this was presented to the court. The judge mandated that she receive computerized tomography of the chest and bronchoscopy with needle-guided biopsy. The patient continued to remain frankly delusional on her haloperidol/olanzapine regimen. The plan was to switch her to clozapine after her pulmonary issues were addressed.

The patient underwent bronchoscopy under general anesthesia against her protests. She claimed that she nearly died from anesthesia years ago during her ECT treatments. On the day of the procedure, she wore a crucifix and stopped wearing her nursing cap for the first time since her admission two months prior. The results of the bronchoscopy revealed small cell carcinoma. She refused to accept the findings, insisting that it was nothing more than a mucous plug and that she could cure herself with her own radiation. It was at this point in the treatment that her sisters began to disagree about pursuing involuntary treatment any further.

The patient would vacillate between acknowledging her disease and denying it, but agreed to have a bone scan and computerized tomography of her head, chest, abdomen and pelvis. The imaging studies revealed that the mass was limited to her RLL. The patient also underwent an experimental peptide nuclear scan, which ruled out micro metastases. The surgery service recommended a right lower lobectomy. A senior psychiatrist interviewed the patient to evaluate her capacity to refuse treatment. During the interview she was grossly disorganized, delusional, and showed no understanding of the nature of her illness and the consequences of refusing treatment. At this point, both sisters felt the patient had the right to refuse treatment and were not in support of the treatment team pursuing court-mandated treatment. The Patient Services Department was contacted to help establish the hospital's position and coordinate legal proceedings with the family.

The cardiothoracic (CT) surgery team was concerned about the patient's pulmonary function and operative morbidity. Pulmonary function tests were obtained and revealed moderately severe obstructive lung disease. A ventilation-perfusion scan revealed that she would have an FEV_1 of 900 cc following her right lower lobectomy (the generally accepted lower threshold for proceeding with surgery is 800 cc (4). According to the senior CT surgeon, surgery was her best chance for a cure, as chemotherapy and radiation without surgery would only be palliative. The oncologists predicted her postoperative five-year survival to be 40% to 50% if the tumor histology was small cell and 60% to 80% if it was non-small cell. Unfortunately, the pathology specimens were inconclusive, showing "mixed" cytology. With this information, the patient returned to court and a judge ruled that she must have the lobectomy. She was very unhappy with the ruling, claiming that she would not wake up from the surgery. Nevertheless, she remained pleasant and cooperative. Her sisters were relieved that they did not have to make the decision, although they still felt that she should not be treated against her will, even if it resulted in her eventual death from cancer.

While awaiting surgery, the patient expressed anxiety about the procedure. She became progressively more subdued and less animated. She stopped wearing her nursing cap and considered herself to be "off duty." She did not resume her identity as a nurse. The patient began discussing paranoid delusions of someone scratching out her eyes or raping her on the unit with greater frequency. At times she would also speak more directly of her fear of dying from complications of anesthesia. On the day of surgery, the nursing staff called the resident psychiatrist and requested that she talk to the patient, who was refusing to go to the operating room. When the resident appeared, the patient begged, "Please don't make me go. I might not wake up." The resident recognized that was a potential outcome, however, it was more likely she would recover well. She had to have the surgery. As the patient left the ward, she yelled, "The Sunshine Kid will be okay!"

The patient underwent a right lower lobectomy and, once stable, was transferred to the Internal Medicine Service where she remained for one month. During that time she developed a moderate right pleural effusion, atrial fibrillation with a rapid ventricular response, and an episode of diabetic ketoacidosis. She was noted to have worsening cognitive function of undetermined etiology and was transferred to the Psychiatry Service for further evaluation and management.

On her return to the Psychiatry Service, she was noted to be markedly impaired, with significant disorganization of thought, perseveration of speech, thought blocking, and disorientation to time and place. She was also observed to have a festinating gait, and was incontinent of urine and stool. A serum B_{12} level was low (157 pg/mL, a drop from 1109 pg/mL one month earlier). Neurology and neurosurgical consultations were obtained. An MRI of the head revealed a pituitary mass suggestive of carcinomatous meningitis, but three lumbar punctures were negative for malignant cells. There was no evidence of hydrocephalus. Her blood pressure and blood sugar were difficult to control, but her gait improved over time. To minimize her medication regimen, the divalproex sodium was discontinued and the plan to initiate a clozapine trial was abandoned. Her affect gradually brightened and her cognitive status improved. She showed further cognitive improvement once her blood pressure and blood sugar stabilized. The patient was discharged after a three-month admission, mildly hypomanic (which her family averred was her baseline) and mildly cognitively impaired with regard to short-term memory and executive func-

tioning. The Neurology and Neurosurgery Services differed in their opinions, but neither could definitively identify the etiology of her postoperative neuropsychiatric decompensation.

Discussion

Although the legal and ethical issues involving this case overlap in content, they are defined differently. The ethical principles will first be defined, and then included in the discussion of the legal issues. This case involves three ethical principles: patient autonomy, capacity, and nonmaleficence. With regard to the first principle, all clinicians are obligated to respect and defend patients' right to choose, thus preserving their autonomy. Capacity, the second principle, is incorporated into the New York State Mental Hygiene Law as the ability to "adequately understand and appreciate the nature and consequences of a proposed major medical treatment, including the benefits and risks of and alternatives to such treatment …" (5) and the third principle, nonmaleficence, refers to the concept of preventing harm or minimizing risks of harm in the treatment of patients (6). A full discussion of these issues is beyond the scope of this paper, however, the interested reader may review several excellent references on the topic (7–9).

The legal issues of relevance are treatment refusal, competence, substitute decision-making, and involuntary treatment. In theory, all patients have the right to refuse both medical and psychiatric treatment based on the common law right of autonomy and freedom of choice. When patients are considered to be of sound mind, they can be given considerable latitude in choosing their treatment, however, when their ability to make rational decisions becomes questionable, they may lose their right to determine their treatment and someone else must decide for them (10). The patient exercised her right to refuse treatment by not returning to the clinic for follow-up of her pulmonary mass. This was similar to her usual noncompliance with her diabetic diet. Her family reported that she had always been cavalier in her approach to medical treatment and they were content with her decisions as long as the patient was content. Once admitted, however, she became subject to clinical scrutiny and was no longer permitted to decide her medical treatment after she was determined to lack the capacity to make informed decisions.

It is important to note the distinction between capacity and competence. Decision-making capacity is based on a clinical assessment, whereas competence is a legal determination. Patients are presumed competent until this is overridden by legal due process. There is no legally established standard for competence, although a review of various court decisions reveals four basic elements that establish a standard: communication of a choice, factual understanding of the issues, appreciation of the situation and its consequences, and rational manipulation of information (11). It is suggested that when no standard has been identified in a jurisdiction, the most conservative approach would be to evaluate the patient based on all four elements and allow the court to decide which areas are most relevant.

In this case, the patient was clearly able to communicate her choice. In fact, she did not waver in her decision when repeatedly asked to express her wishes. This suggests a stability of choice. A competent person should also be able to show at least a minimal understanding of the factors involved in the decision. She experienced considerable difficulty here, vacillating between considering her ailment to be the result of a mucous plug and acknowledging that it was cancer. Despite multiple explanations, she also could not understand the basics of the procedure she was refusing. When asked what she thought the consequences of her refusal would be, she said that she would be "fine" because "the radiation from my own sunshine will cure me and the mucous plug will disappear". Not only could she not appreciate the severity of the consequences of her refusal, she had no appreciation for the benefits of procedure. Rational manipulation describes the process by which a patient algorithmically works through the benefits and risks of a decision (11). This patient's reasoning was psychotic and had no logical foundation. Her basic denial of illness precluded her from being able to process the situation in a sound manner.

The threshold at which one chooses to consider someone incompetent can vary depending on the context to which it is applied. Some call for stricter standards when the issue involves treatment of life-threatening decisions. For example, one may use more lenient standards for determining that someone is incompetent to write a will than one would when that individual is refusing medical treatment. Even the threshold for *consenting* to necessary treatment in a patient with questionable capacity may be lower than that for the same patient who wants to refuse necessary treatment (12). In this case, the patient failed three out of four standards, which clearly demonstrated her incompetence.

Competence can be a dynamic state. Reversible agents may influence one's capacity to make decisions about his/her treatment (e.g., treatable psychiatric conditions such as depression, delirium, and noncompliance with medication leading to worsening mental state). It has been well described that patients with psychotic defenses can experience changes in their level of competence under stress (13). According to the staff at the residence, the patient appeared to be functioning well until she learned the results of her chest X-ray, following which she became increasingly delusional. It is not entirely clear that she ever had a completely psychotic-free existence, and it is also difficult to know what functioning "well" means in terms of her capacity to make medical decisions; however, despite her overt denial of cancer and her delusions built around it, there were times in which she seemed to have some minimal insight. For instance, at times she would adamantly state that she had a mucous plug, not cancer, yet her next association would be fear that another patient on the ward was dying. Had her fears been explored in greater depth, her defenses may have been worked through and a better understanding of her refusal might have been achieved. This may also have helped her formulate a more rational manipulation of the facts and subsequently form a more logical algorithm for her decision. Unfortunately, given the urgency of her condition, this type of psychodynamic exploration would require more time than was allowed.

The third legal issue, substitute decision-making, also has clinical significance. There are three different classes of decision-makers: guardians appointed by the court, judges, and informal decision makers. Informal decision makers can be family or friends who make decisions for the incompetent person without being formally appointed; however, when the procedure being prescribed is considered extraordinary, a judge automatically assumes the role of decision-maker. As indicated earlier, this usually includes sterilization, surgery and ECT, but varies depending on the state. In these cases of extraordinary care, even appointed guardians are unable to consent for the patient (9).

Clinical Implications

The last legal issue, involuntary treatment, is a clinical decision that follows a patient's treatment refusal. In the case of a psychotic patient refusing neuroleptics, who presents as a danger to self or

others, it is a relatively straightforward decision to pursue involuntary treatment. The decision to violate the patient's right to refuse treatment is easily justified by implementing the patient's right to receive treatment when he is unable to make this decision for himself.

In this case however, the right lower lobectomy carried significant risks. The 1983 Lung Cancer Study Group reported a postoperative mortality of 2.9% in patients undergoing lobectomy at academic medical centers. A California study reported a rate of 4.2% in patients treated at community hospitals (14). Given this patient's chronic obstructive pulmonary disease and her other medical problems, the morbidity and mortality associated with a lobectomy were significant. In fact, her poor anticipated post-resection pulmonary function placed her just above the threshold for inoperability (4). In these circumstances, is it fair to say that a patient's refusal, irrespective of her competence, should not be taken into account? This decision was deferred to a judge who had no medical expertise. How can he determine what was in the best interests of the patient? The hospital petitioned to pursue treatment, but how could they claim to represent the patient's best interests? In cases such as this, clinicians and the courts run the risk of projecting their own best interests based on their own feelings about what should be done.

Even though the judge resolved the dilemma, the physicians were responsible for enabling him to make a medically informed decision. The attending CT surgeon, oncologist and psychiatrist provided this necessary information. Undoubtedly each entered the courtroom with his personal opinion about what action should be pursued. Although I was the resident on the case and did not have this responsibility, it has been important to reflect on what my actions would have been. Over the three months that I managed this patient's care, I had become very fond of her. I became very protective of her as well. When she begged me to let her stay on the ward and refuse the surgery, I felt that I was sending her off to the slaughter. Perhaps I identified too much with the patient and her need to make her own decisions about her life. After all, who was I to say that it was not acceptable for her to die of cancer if she so chose?

During my discussions with the CT Service, I became concerned about her surgical risk. Furthermore, it was not clear to me that proceeding with surgery was the right decision. I saw her as a mentally compromised woman who had lived rather peacefully for 62 years despite her tenuous compliance with medical treatment. I felt that, even though she was chronically paranoid, her fears of dying from the surgery had some realistic basis. Although either action bore some untoward consequence, it is possible that the patient's best interests were best met by preserving her autonomy at the expense of her physical well being. Had I been empowered with the task of presenting her case to the judge, my counter-transference feelings may have hindered my objectivity.

Epilogue

I saw the patient informally two years later, just prior to this writing. She continues to be seen for treatment in the outpatient psychiatric clinic. That day, she was dressed in a black suit that was similar to the one she wore on the unit and donned the same black, "off duty" cap. Although she immediately recognized my face, she did not remember my name. She now lives with one of her sisters and volunteers every day at a senior center. I asked her what she remembered of her inpatient stay. Her first recollection was that "a patient was killed." She failed to elaborate on this or on her thoughts about who was killed. The patient remembered being on the unit "doing my work" and did not see herself as a patient. With heavy prompting she recalled being told that she had a lung tumor, but maintained that it was a mucous plug. Moreover, she remembered having surgery against her will, but could not understand why the doctors would do such a thing. She wondered if the judge was still practicing law, then rattled off several other involuntary surgeries she claimed to have had in the past, including the removal of her eyes and breasts, and several rapes with instruments. The patient wore a badge from the senior center and referred to the people there as her clients, but said that she has never worn her nursing cap again. She gave me a copy of her state nursing license as a "souvenir." I was surprised that it was current, because I had questioned her professional abilities and the legitimacy of her claim that she was still a nurse.

In retrospect, it appears that treating her involuntarily was the right decision, as she is now functioning well physically. Nevertheless, I still wonder what impact the involuntary treatment had on her. In this case, the prescribed treatment saved her life. But did it? What effect did it have on her psyche? I was struck by her opening statement that her only recollection of her admission was that a patient on the unit was killed and wondered if she was referring to herself and her identity as a nurse. Even though she survived the surgery, her statement suggests there was some death in her mind. In keeping with our duty of nonmaleficence, should we have aborted our efforts to force the surgery if we had known it would alter her sense of self? Given the legal precedent for due process in the case of extraordinary care, we would have pursued the same course. But *should* we?

The courts have answered this in the affirmative because we have determined that physical health and well-being supercedes the state of one's mind. Though it is not clear the extent of this patient's losses, her associations to the surgery were of being raped and having body parts removed. This suggests that she experienced the surgery as a catastrophic insult and is unable to balance the positive and negative aspects of the surgery. Should we have expected anything less from the involuntary removal of a body part in a psychotic patient?

Perhaps a person should have the right to retain a body part even if it is diseased. The adjudicatory process does not consider these issues when determining competency and mandating treatment. Practically speaking, it would be exceedingly difficult to develop a procedure for incorporating these extenuating circumstances. It would take years of exploration to uncover even a portion of her fantasies about the surgery and its relationship to her identity to the degree necessary to base a competence decision. Given the urgent nature of these extraordinary care circumstances, it is doubtful that exploratory practices will ever be employed as a decision-making tool.

Conclusions

What can one learn from this case? Perhaps the greatest dilemma I faced was balancing the obligation to treat this patient in a way that promoted her well being while at the same time, respecting her autonomy. With regard to patient well being, it was the physician's responsibility to present a clinical opinion to the court on behalf of the patient. This was a difficult dilemma and the clinician's own counter-transference toward the patient has to be examined as it can obstruct one's impartiality. To avoid this pitfall, the physician can consult a respected colleague to help construct a dispassionate recommendation.

In terms of preserving patient autonomy, knowing that competent patients have the right to dictate their treatment, it would be

prudent for clinicians to assist their patients in being proactive. The first step involves the establishment and execution of an advance directive. For many patients this is an unfamiliar subject. In this case, if the patient had an advance directive (i.e., a living will and designation of a health care surrogate), her refusal of treatment would have been upheld and the clinicians would have been assured they were honoring the patient's wishes, even if this may have appeared to be an unwise medical decision. Establishing an advance directive is especially important for patients with mental illness whose capacity to consent to or refuse treatment may fluctuate with the state of their illness.

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