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**HUMAN RIGHTS AUTHORITY- CHICAGO REGION**

**REPORT 14-030-9026**

**University of Illinois Medical Center**

**INTRODUCTION**

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at University of Illinois Medical Center. It was alleged that the facility did not follow Mental Health Code and Illinois Power of Attorney Act mandates when it did not honor a recipient's Power of Attorney for Healthcare. If substantiated, this allegation would be a violation of the Mental Health and Developmental Disabilities Code (405 ILCS 5/100 et seq.) and the Illinois Power of Attorney Act (755 ILCS 45).

The University of Illinois hospital is a 507-bed facility with more than 40 primary and specialty outpatient clinics. The Department of Psychiatry offers a full range of general psychiatric services as well as five specialty programs, and the inpatient program serves up to 37 patients.

To review these complaints, the HRA conducted a site visit and interviewed the Assistant Head of Clinical Services, the Safety and Risk Management Officer, the Patient and Guest Experience Officer, the Director of Psychiatric Social Work, the Director of Accreditation, the Associate Director of Nursing, the Director of Patient Care Services for Psychiatry, and the Associate Director of the Inpatient Unit. Hospital policies were reviewed, and the recipient's clinical records were reviewed with written consent.

**COMPLAINT**

The complaint alleges that the Power of Attorney (POA) for the recipient had sent a letter to UIC Hospital that she did not want the recipient to have medication, especially medication which required the recipient to have his blood drawn. The complaint alleges that the hospital nonetheless initiated two medications, Perphenazine and Clozapine, and the recipient reacted very negatively, having memory lapses and depression. When the hospital increased the

Perphenazine to 30 mg, the complaint alleges that the recipient's personality changed dramatically for the worse, which the POA agent pointed out to hospital staff. The complaint indicates that the recipient's physician knew that the POA agent did not want the recipient to have his blood drawn, however he prescribed a medication that because of its dangerousness required almost daily blood draws.

## FINDINGS

The record contains the recipient's Admitting History/Physical completed 12/19/13. It states, "Pt. is a 25 y/o single, domiciled, unemployed AAM with past psychiatric history of mood/psychotic disorder who presents to ED from his residence states- The spiritual voice states, 'I will die on the 12/21/13' which somehow is involved with the Mayan calendar. Pt further states that his death will be by 'drowning' and will be perpetrated by his mother unconsciously and symbolically and will make her an abomination who will die from grief.' Pt. denies active SI/HI [suicidal ideation /homicidal ideation]. Pt. also believes he is being conspired against by the 'SPEC Nazi's', (a Russian Nazi organization), because he is a threat to white race as well as by the FBI and the Republicans.' Pt states that he needs to shower 5 times daily in order to concentrate and he believes 'his food is cursed' and consequently he repeatedly 'vomits up his food.' Pt. asserts that he is 'depressed and wants to die' because he cannot tolerate living in his mother's 'unstructured' environment. Pt. denies experiencing frank manic symptoms. Pt. does not endorse visual hallucinations and his current audio hallucination itself described as 'like spiritual soft water' appears to be egosystonic, although the thematic content involves his death." The recipient's diagnosis is listed as Psychosis NOS (not otherwise specified) with a note indicating Bipolar Affective Disorder, most recent episode manic with psychotic features. The Admitting Treatment Plan indicates that the recipient will continue his psychotropic medications from home which include Carbamazepine, Lorazepam, and Perphenazine. The physician statement of the recipient's decisional capacity is included in the Admitting History/Physical and the patient is accepted as a voluntary admittee.

The record contains four discharge summaries which describe in detail the recipient's hospital course:

*1. Pt. has been admitted on 12/19/13 to Dr.... He was restarted on his home medications and monitored on close observation for CAH [command audio hallucinations]. Pt at first refused to eat due to feelings that food was poisoned. Pt. initially very paranoid. Perphenazine dose has been titrated up to 30 mg BID, and patient has mildly improved. He still hears CAH and is disorganized, however is eating at this time. Primary team to continue to monitor.*

*2. Care was transferred to Dr... 12/27. Dr... continued to supervise the case. He was continued on perphenazine 30 mg bid, and his psychosis continues to slowly resolve, though disorganized behaviors continue, especially regarding the shower/tub. He was transitioned to general precautions on 1/2/14 without incident, though there should be a low threshold for reinitiating CVO [constant visual observation] due to previous severe decompensation and SI with CAH. He was switched from lorazepam to clonazepam 0.25 mg each 12 hours for anxiety, which he tolerated well. Due to the seemingly episodic nature of his psychosis, an EEG was performed on 12/31 which revealed unilateral slowing. Neurology was curbsided and unconcerned for current seizures, stating slowing most likely 2/2 history of multiple traumatic brain injuries. Recommend formal neuro consult if patient has witnessed seizure-like activity.*

*He is a candidate for clozapine, baseline labs have been done, and he has been provided written information on clozapine. Initiation of clozapine has been postponed due to pt.'s recent clinical improvement. He is compliant with meds and attends select groups.*

*3. Care was transferred to Dr... Dr... continued to supervise care. Pt. was initially taking perphenazine 30 mg bid. However, he continued to demonstrate psychotic symptoms, including lying in the shower for long periods of time, describing plans to get on X- Factor after discharge, and having superpowers, e.g., X-ray vision. Further, pt developed an episode of acute dystonia, involving problems with eye tracking and controlling his gaze, as well as some neck stiffness, both of which resolved with administration of IM [intramuscular] benztropine. Pt was started on scheduled benztropine 1 mg each 12 hours. The decision was also made to switch patient's perphenazine to clozapine. Pt demonstrated capacity for informed consent. He understood his illness, reasons for taking antipsychotics, risks and benefits of clozapine, as well as alternatives. He also understood the monitoring associated with clozapine, and was amenable to starting it. Clozapine titration was started per Teva table on 1/11/14.... On 1/19/14, he developed increased heart rate .... His clozapine titration was slowed; however, it was continued on the regular titration schedule after that. Pt continues to have psychotic symptoms, and showed recent re-emergence of sexual acting out. He was moved to the south side of the unit because he exposed himself on 1/24/14. Will continue to monitor pt's psychotic symptoms. Pt will also have a family meeting on 1/30/14 at 11 am with his mother. Team recommends that pt be discharged to a place like [a group home] which could assist with transitioning to work, etc. However, pt states that he wants to go home because his mother is sick, and further, he wanted to move to California to participate in the X-factor competition.*

*4. Care transferred from Dr...1/27/14. Since that time, treatment team continued to titrate up Clozapine to 150 mg daily/250 mg at bedtime. Pt has responded well to medication and not endorsed any S/E [side effects] which were monitored daily. Psychotic and mood symptoms resolved and pt able to participate in group activities on the unit. Pt has had weekly CBC [complete blood count] w/diff to monitor WBC [white blood cell] and ANC [absolute neutrophil count] which have been WNL [within normal limits]....*

*Stable and improved. An examination at the time of discharge was not depressed or suicidal. The patient denied auditory hallucinations, paranoid thoughts, or homicidal ideation and was able to care for basic needs....*

An addendum to Inpatient Progress Notes written 2/01/14 by the physician describe some of the toxicity issues involved in the administration of Clozapine: As per lab, Toxic range: Greater than 2000 ng/mL [nanograms per decileter]. Clozapine concentrations between 100 and 700 ng/mL may correlate more with clinical response; however, non-responsiveness may occur within this range. For refractory schizophrenia, 350 ng/mL of clozapine is suggested to achieve a therapeutic response. After initial therapeutic response occurs, the dose should be progressively reduced to the minimum level necessary to maintain clinical remission. The likelihood of seizures and other side effects increase with clozapine levels greater then 1200 ng/mL and/or dosages greater than 600 mg/24hours. Toxic concentrations may cause hypotension, cardiac abnormalities, respiratory depression, coma and death."

Progress Notes from the recipient's clinical record reflect discussions regarding his medications:

1/03/14 Inpatient Progress Note. ...He [recipient] is a candidate for clozapine, baseline labs have been done, and he has been provided written information on clozapine. Initiation of clozapine has been postponed due to pt.'s recent clinical improvement. He is compliant with meds and attends select groups.'

1/09/2014 Psychiatry Note. ROD [resident on duty] was paged by [pharmacy] at 9PM, because patient's current dose of perphenazine is higher than recommended daily dose. Per [pharmacy],

maximum daily dose is 12 mg BID or 24 mg daily. ROD informed [pharmacy] that patient's primary team has documented that medication is necessary for patient's continued psychosis. No medication changes made by ROD or [pharmacy] at this time. [Pharmacy] will page primary team in AM to discuss further.

1/09/14 Inpatient Progress Note. ...Later, spoke with patient about starting clozapine. Pt was able to understand his illness, reasons for taking antipsychotics, risks and benefits of clozapine, as well as alternatives. He also understood the monitoring associated with clozapine, and was amenable to starting it.

1/10/14 Social Work Notes. Contacted pt's mother to notify her that pt revoked the POA. She is very upset that pt wants to go to a group home. She does not feel this is the best decision for the pt. Pt will contact her on Monday to discuss.

1/11/14 Psychiatric Inpatient Note. Affect and mood is sad. Denied thoughts of si/sh, denied a/v hallucinations. When asked about his thought process on the previous shift, why he received PRN, 'I thought I was hearing voices but it was the nurse voice that I heard.' Thought process is disorganized, appears preoccupied at times. Mother called and concerned about the use of clozapine about the warning signs involving the heart, 'my son has a heart problem.' Mother was instructed to talk with the treatment team regarding her medication concerns. Pt. said that he feels good with his medication. Pt. calm and cooperative. No behavioral problems noted.

1/13/14 Inpatient Progress Note. Spoke with pt.'s mother, who stated that she continues to be concerned about the clozapine that pt. is on. She stated that further, she talked to pt, who stated that he will stop taking the medication after he comes home. Writer talked again with patient. Discussed the reasons he is taking psychotropic medications, specifically clozapine ('Voices', 'to help make my thoughts clearer'), as well as the risks, benefits, and alternatives to the medication. Pt voiced understanding and verbal consent. He stated that he initially told his mother this, but that he changed his mind, and wants to take his medication. He understood the risks of stopping and restarting the medication on his own, and stated that he plans to take it long-term, and only stop it under the supervision of a doctor.

1/28/14 Inpatient Progress Note. No acute events overnight. No PRNs required. Compliant with scheduled meds. Pt eating meals and sleeping at night. As per nursing, pt reported AVH [audio visual hallucinations], which pt denies on today's exam. Pt states that he feels better today and that his 'strength has improved.' Pt states that he is debating whether to return home vs [group home].

As per mother, saw him last Sunday (19<sup>th</sup>). Mother states that at this time he was forgetting things, eg what he had for breakfast. Also notes that he had lost sense of humor and appeared 'ashen'. Previously having difficulty with sleep. Mother notes that pt follows up at UIC and will try to get him to weekly appointments although it will be challenging. Also, mother is concerned about drug use of patient..."

2/08/14 Inpatient Progress Note. In bed but awake. Easily engaged. Denies AH now that he is on clozapine. Today he denies any side effects from the medication, although he is in bed at 10AM. He feels the medication has helped him and taken away the voices and he says he will take the medication when he is discharged.

2/10/14 Inpatient Progress Note. ...As per mother, she is concerned that patient is sleeping during the day and not at night. She is also concerned that he is more irritable towards mother over the phone, asking why she is 'getting in his business.' She states that his oppositional behavior reminds her of when he was 16 yo. She does not feel that he is ready to come home based on his sleep pattern and irritability. Regarding [group home], mother is concerned that pt will use any excess money to buy cigarettes and alcohol. She does not think he will be able to

*function in a facility. She is not pleased about Clozapine follow-up but will keep not discontinue med and will help facilitate weekly follow-up.*

*2/10/14 Inpatient Progress Note. Today patient stated that he is doing well. He denied any SI, HI, or AVH. He spoke about how he is not feeling quite as good as 'Superman', but that right now, he is like 'Batman.' He denied having any superpowers. He spoke again about how he would like to go to [group home], and also talked again about how he would like to switch to clozapine. Later, spoke with pt.'s mother, who noted that she would not like for patient to be started on clozapine. She stated that she read the information that was printed, and that she was concerned about the side effects. Mother also stated that she is the power of attorney and requested that the writer look at the documents. Spoke with her about how the side effects of clozapine would be closely monitored, and that it will be discontinued if any serious side effects were to manifest. Looked at power of attorney of healthcare with social work, and talked again with patient about it. Pt verbally revoked the power of attorney in front of writer and social worker.*

*2/10/14 Social Work Note. Writer spoke with Pt.'s mother. Pt.'s mother is not in favor of the Pt. being discharged soon. Pt.'s mother would like the Pt. to stay longer. [POA agent] stated, [recipient] is so much moodier now, he used to smile and laugh a lot more before this medication.' [POA agent] expressed concerns about the Pt.'s medicine. [POA agent] does not support the plan for the Pt to be seen at [local hospital] for both blood work and day program. Writer explained due to the pt.'s insurance that [specified hospital] is the closest hospital, and has openings to follow up with him. Pt.'s mother would prefer for the Pt. to be seen here at UIC hospital. [POA agent] was inform that there is no openings in the clinic. [POA agent] verbalized understanding. [POA agent] ended the conversation by stating, 'I'm not afraid of him, I just think he should stay longer.'*

The record contains the document signed by the recipient on 10/04/06 naming his mother as his Power of Attorney for Healthcare. It indicates that the recipient's "firmly held religious convictions" and his awareness of the risks of blood, necessitate that "I absolutely, unequivocally, and resolutely refuse allogeneic blood (another person's blood), and stored autologous blood (my blood), under any and all circumstances, no matter what my medical condition." The document states that the Power of Attorney is effective as long as the recipient is incapable of making his own healthcare decisions.

#### Hospital Representatives' Response

Hospital representatives were interviewed about the complaint. They indicated that the recipient maintained decisional capacity from the time of his entrance to the emergency department and throughout his hospitalization at UIC. Staff indicated that he was able to understand his illness and his need for medication and was willing to accept the side effects of his medication in order to improve his symptoms. Staff indicated that the recipient was able to seek out staff even when he experienced audio command hallucinations and was able to interrupt his symptoms by eliciting help. Although the staff included the recipient's mother in his care, he was able to make decisions regarding his medication, and then eventually he revoked his POA after being counseled about it twice, once on 1/09/14 and again on 1/10/14. He had expressed a desire to revoke the POA on 1/09/14 however staff had counseled him to think about this for a week, which he did, and then he made the decision to revoke the POA. Staff indicated that the recipient had been hospitalized at UIC two months previous to this hospitalization and throughout that time the recipient's mother never indicated that she was the POA for the recipient. They indicated that the recipient was a voluntary admittee for the most recent hospitalization, and was deemed appropriate for this status. Staff indicated that they were made aware of the recipient's POA only after he had been hospitalized several weeks and that the recipient himself did not reveal this information in his admission information, when recipients are traditionally asked about substitute decision makers.

Staff were interviewed about the recipient's medication. They indicated that the recipient had a long history of very serious mental illness and had been prescribed numerous medications that did not resolve his command hallucinations to harm himself. When his physician recommended the medication clozapine, the physician and the recipient had several lengthy discussions about the drug, namely that it requires a lengthy period in which to reach a stable therapeutic level, and that close monitoring would be necessary to achieve and maintain it. The recipient was amenable to the plan and agreed to the medication. As the record reflects, the POA agent also agreed to the plan to continue Clozapine (2/10/14), even though she was concerned about health issues and the need for blood draws.

## STATUTES

The Mental Health Code provides guidelines for the administration of psychotropic medication:

"(a-5) If the services include the administration of...psychotropic medication, the physician or the physician's designee shall advise the recipient, in writing, of the side effects, risks, and benefits of the treatment, as well as alternatives to the proposed treatment, to the extent such advice is consistent with the recipient's ability to understand the information communicated. The physician shall determine and state in writing whether the recipient has the capacity to make a reasoned decision about the treatment. The physician or the physician's designee shall provide to the recipient's substitute decision maker, if any, that same written information that is required to be presented to the recipient in writing. If the recipient lacks the capacity to make a reasoned decision about the treatment, the treatment may be administered only (i) pursuant to the provisions of Section 2-107 or 2-107.1 or (ii) pursuant to a power of attorney for health care under the Powers of Attorney for Health Care Law [FN1] or a declaration for mental health treatment under the Mental Health Treatment Preference Declaration Act. [FN2] A surrogate decision maker, other than a court appointed guardian, under the Health Care Surrogate Act [FN3] may not consent to the administration of authorized involuntary treatment. A surrogate may, however, petition for administration of authorized involuntary treatment pursuant to this Act. If the recipient is under guardianship and the guardian is authorized to consent to the administration of authorized involuntary treatment pursuant to subsection (c) of Section 2-107.1 (court ordered medication) of this Code, the physician shall advise the guardian in writing of the side effects and risks of the treatment, alternatives to the proposed treatment, and the risks and benefits of the treatment..." (405 ILCS 5/2-102).

The Mental Health Code states, "An adult recipient of services, the recipient's guardian, if the recipient is under guardianship, and the recipient's substitute decision maker, if any, must be informed of the recipient's right to refuse medication. The recipient and the recipient's guardian or substitute decision maker shall be given the opportunity to refuse generally accepted mental health or developmental disability services, including but not limited to medication. If such services are refused, they shall not be given unless such services are necessary to prevent the recipient from causing serious and imminent physical harm to the recipient or others and no less restrictive alternative is available. The facility director shall inform a recipient, guardian, or substitute decision maker, if any, who refuses such services of alternate services available and the risks of such alternate services, as well as the possible consequences to the recipient of refusal of such services" (405 ILCS 5/2-107). Additionally, the Code states that whenever any rights of the recipient of services are restricted, notice must be given to the recipient, a designee, the facility director or a designated agency, and it must be recorded in the recipient's record (ILCS 405 5/2-201).

The Illinois Power of Attorney Act states that, "The health care powers that may be delegated to an agent include, without limitation, all powers an individual may have to be informed about and to consent to or refuse or withdraw any type of health care for the individual and all powers a parent may have to control or consent to health care for a minor child" (755 ILCS 45/4-3).

The Illinois Power of Attorney Act details the duties of health care providers and others in relation to health decisions made by POA's:

"Each health care provider and each other person with whom an agent deals under a health care agency shall be subject to the following duties and responsibilities:

(a) It is the responsibility of the agent or patient to notify the health care provider of the existence of the health care agency and any amendment or revocation thereof. A health care provider furnished with a copy of a health care agency shall make it part of the patient's medical records and shall enter in the records any change in or termination of the health care agency by the principal that becomes known to the provider. Whenever a provider believes a patient may lack capacity to give informed consent to health care which the provider deems necessary, the provider shall consult with any available health care agent known to the provider who then has power to act for the patient under a health care agency.

(b) A health care decision made by an agent in accordance with the terms of a health care agency shall be complied with by every health care provider to whom the decision is communicated, subject to the provider's right to administer treatment for the patient's comfort, care or the alleviation of pain; but if the provider is unwilling to comply with the agent's decision, the provider shall promptly inform the agent who shall then be responsible to make the necessary arrangements for the transfer of the patient to another provider. It is understood that a provider who is unwilling to comply with the agent's decision will continue to afford reasonably necessary consultation and care in connection with the transfer" (755 ILCS 45/4-7 Sec. 4-7a and b).

## HOSPITAL POLICY

UIC Hospital provided policy and procedure regarding Advance Directives (No. RI 4.02). The objective of the policy is described, "To recognize and support patient autonomy and the rights of patients with Decisional Capacity to participate in decisions regarding their health care, including the right to refuse medical and/or surgical care, make decisions regarding life-sustaining treatment and otherwise express preferences and instructions in writing pursuant to Advance Directives." The policy describes Durable Power of Attorney for Health Care as "a document, voluntarily produced by an individual. Which delegates another person to act as his/her 'agent' for health care decisions should that person lack decisional capacity and/or be unable to make health care decisions for themselves."

## CONCLUSION

The clinical record for this recipient, along with staff interview, indicates that the recipient was determined by his physician to have decisional capacity throughout his hospitalization at UIC. Although the record shows that the recipient was given written and oral information regarding the Perphenazine and Clozapine medications he was prescribed, along with the side effects, risks, and benefits of their administration, the record does not document that he was given the same information on his other prescribed psychotropic medications. The record also shows that the POA agent was included in the discussions with the treatment team regarding the recipient's care even after her agency under POA was revoked, and that she agreed to the continuation of the prescribed medication regime. Psychiatry Notes and Social Service Notes indicate that the recipient initiated the discussion of revoking the POA and he was asked by his counselor to postpone this decision until he was certain that he wanted to go forward with revoking it. The HRA does not substantiate the complaint that UIC Hospital did not follow Mental Health Code and Illinois Power of Attorney Act mandates when it did not honor a recipient's Power of Attorney for Healthcare

### SUGGESTION

1. Ensure that all recipients and substitute decision makers are given information, in writing, of the side effects, risks, and benefits of treatment, as well as alternatives to the proposed treatment and that this is documented in the record.
2. Ensure that POAs are in effect when including a POA agent in treatment planning and in treatment planning decisions. If not in effect, ensure recipient agreement with including others in treatment planning.