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Northwest Regional Human Rights Authority
Report of Findings
Case #: 20-080-9007
UW Health/SwedishAmerican Hospital- Rockford, IL

Introduction

The Human Rights Authority (HRA) opened an investigation into potential right violations of a patient at UW Health/SwedishAmerican Hospital in Rockford. T**he complaints are that a patient was not given the right to refuse services and medication and denied the right to choose or use the statutory health care Power of Attorney agent**. Substantiated findings would violate protections under the Mental Health and Developmental Disabilities Code (405 ILCS 5) and the Illinois Power of Attorney Act (755 ILCS 45).

UW Health/SwedishAmerican Hospital, is a division of the University of Wisconsin Health System. Per the website, UWHealth/SwedishAmerican Hospital is the "only heart hospital in the region and the largest regional cancer center". This hospital location has a 339 acute bed capacity, an inpatient II trauma center and a psychiatric program, referred to as the Center for Mental Health (CFMH). The HRA conducted two teleconference visits and discussed the case with representatives from the CFMH, Emergency Department (ED) personnel and administrators. Relevant policies were reviewed as was the patient's record with authorization. Many of the providers and residents who saw the patient are no longer associated with the hospital system.

Complaint Summary

The complaint alleges that the hospital personnel did not properly educate the patient on their rights, did not allow the patient the right to choose their care plan or treatment and did not include their agent under a Power of Attorney (POA) for health care in various medical decisions especially surrounding the appropriate psychotropic medication regimen during the months of February 2018 – March 2018.

Record Review

There were numerous medical records to review during the reported complaint time period, which covered February 2018 – March 2018 and this report covers various hospitalizations from January 2018 through March 2018. The hospitalization dates are as

follows: January 30, 2018, through February 26, 2018, March 6, 2018, March 14 through March 19, 2018, and March 19 through March 31, 2018. This record review will focus on each hospitalization, patient, POA agent and hospital personnel interactions. It is safe to note each admission had the same agent under the POA listed. The POA listed on the "***Statutory Short Form Power of Attorney for Health Care"*** document had "broad" decisional authority to "make health care decisions for the patient, which includes the power to acquire, consent to , or withdraw treatment for any physical or mental condition, and to admit or discharge patient from any hospital, home or any other institution throughout the patient's lifetime." The form also states that if a specific time period is not selected, the power of attorney "agent may exercise the powers given to him or her throughout your lifetime, even after you become disabled."

Medical Record Review

Hospitalization: January 30, 2018 - February 26, 2018

The patient initially arrived at the emergency department (ED) via emergency medical services for complaints of abdominal pain at 10:05pm on January 30, 2018, and the hospital staff was in contact with the POA agent at 10:16pm to get a better picture of the patient's aliments, medical history and the reason for the hospital visit. On February 1, 2018, the attending physician spoke with the POA agent who requested consultations with the following specialists: Infectious Disease, Gastrointestinal, and Urology for the patient, which all consults were completed, and necessary medical treatment was provided.

On February 16, 2018, an evaluation consultation for capacity on the patient was completed and the following recommendations was provided: *" patient does have capacity to make decisions in his own best interest, he is able to hold his problems in consciousness, able to discuss consequences of refusing to go home, as well as comprehension of alternatives. Would defer any psychotropic medications until the patient seen as outpatient by his primary physician. Patient might benefit from subacute rehab due to his continued physical needs. However, this must be determined by the primary team."* On this same day, the attending physician spoke with the POA agent and provided the following diagnosis: "the patient is decisional, medically cleared and ready to go home". At this time the POA agent, was unavailable to discharge and take the patient home. The next day the nursing staff and case manager spoke with the POA agent and provided insight that the patient was responding well to treatment and discussed the treatment plan and services that will be provided. Immediately following the phone conversation with the POA agent, the individuals met with the patient and discussed the proposed treatment plan, and it was reported there were no questions.

On February 18, 2018, while meeting with the Advanced Nurse Practitioner (APN), it was reported the patient was medically stable and ready for discharge but there were reports of the patient experiencing anxiety. The APN suggested to possibly meet

separately with the patient without the POA agent (since it was determined that the patient has capacity) to evaluate the anxiety. Initially the POA agent was not in agreement with this suggestion and kept stating that the patient wanted the POA agent present, eventually the patient agreed to meet separately with the APN. After meeting, it was shared that the patient requested a medication for anxiety and a low dosage was prescribed. The POA agent had additional questions regarding placement options, and the APN referred the conversation back to a caseworker and the nursing team. The patient was discharged on February 26, 2018, to a sub-acute facility.

Hospitalization: March 6, 2018

The patient returned to the hospital on March 6, 2018, for a medical complaint per the POA agent, from a sub-acute facility at 12:28am The patient was examined and did not report any pain or receive any medications. The attending physician spoke with the POA agent at 2:12 am regarding the course of action and the patient was released back to the acute facility at 2:31am.

Hospitalization: March 13 – March 19, 2018

On March 13, 2018, the patient and POA agent returned to the ED with complaints of breathing problems and other medical issues at 12:53am. After a few tests were completed, the patient was admitted for treatment and services. The POA agent provided verbal and written informed consent for surgery of a nephrostomy tube insertion on March 14, 2018. Both the POA agent and the patient were given the opportunity to ask questions and both stated understanding and agreeing the surgery was the ultimate option to pursue. Later after surgery, around 8:00pm, the POA agent had paged several service providers who were treating the patient, unfortunately none were available, but the hospital provided a physician to observe instead. Another request was submitted by the POA agent for a chaplain visit and services. The POA agent called for an update, for which the unit nurse spoke with the patient, and it seemed the POA agent was satisfied with the information. Per the medical records, on March 15, 2018, during the day, personnel was concerned that the patient might be "developing sepsis" but did not meet the criteria. Later in the night, the unit nurse reassured the patient, who constantly activated the nurse call light, even when a sitter was in the room. It was decided to reach out to the nursing supervisor to provide a tele sitter for the patient.

On March 17, 2018, the patient continued to constantly push the nurse's call button, even when a nurse was present in the room. Later in the evening, the POA agent was asking for providers to be paged to come and see the patient and run various tests and it was relayed to the POA agent that there was a meeting set for the next day and any all questions would be answered along with discussing test results. The next day, the patient displayed anxiety whenever a nurse left the room. The doctor met with the patient on March 18, 2018, and reported there was some improvement, but also some concern, due to some requested changes to psychotropic medication. During the early hours of March

18th, the unit nurse observed that patient was "increasingly agitated" and inquired if the patient was "having anxiety" and the patient responded "yes". The nurse asked and offered the patient medication to assist with anxiety and the patient stated "yes" to the offer; the nurse educated the patient on the prospective dosage of Haldol PO and the patient agreed to take it at 3:38am The patient continued to have anxiety at night and through the overnight hours, in which a unit nurse would periodically sit with the patient to calm his anxiety. On March 19, 2018, at 1:15pm, the patient was discharged back to a sub-acute facility with follow-up appointments scheduled.

Hospitalization: March 19– March 31, 2018

On March 19, 2018, the patient returned to the ED at 7:54pm, with complaints of an altered mental status; during the evaluation assessment, neither the patient nor POA agent could pinpoint the exact issues of concern, but the patient was admitted for observation after numerous tests were completed at 11:08pm. The next day, per the records received the patient was categorized from inpatient to being on observation status, which entails an outpatient status and receiving observation services. In the afternoon, around 1:20pm, the attending physician wrote in the records that he was asked not to visit the patient per the POA agent. After receiving consultation from the hospital administration, the physician visited the patient who was alert and oriented. A discussion was had surrounding current diagnosis and treatment options, in which the patient seemed to understand and agreed to the treatment plan, per the records.

On March 22, 2018, around 7:24am, it was documented that the patient's vitals were stable , he showed continuous improvement and was observed to be walking through the halls. At 11:30am, while visiting with the attending physician , the patient was still in agreement with the treatment plan and awaiting follow-up from the case manager surrounding discharge options. The attending physician followed up with the POA agent and the patient on what the current treatment plan would be and both parties agreed and understood the plan, after having all their questions answered.

During the morning rounds on March 23, 2018, the physician checked in on the patient, who reported having breathing issues and the treatment plan was discussed and the patient agreed with the plan, around 7:27am. Later that morning, the attending physician answered the patient's questions and discussed the patient's status and options, along with risk and benefits to which the patient agreed. The agreed patient's plan that the doctor referenced included the following: muscle pain and treatment mentioned by patient, continuing the same medication regime that the patient has been following with a slight change in holding off on some psychiatric mediations due to current positive mental status report, consideration of an air mattress and continued practice of breathing exercises.

On March 24, 2018, the patient who was in stable condition and ready for discharge, saw the attending physician, discussed the treatment plan, and was ready for discharge whenever the POA agent could come and pick up. Per the progress note, the attending doctor read that for discharge "subacute rehab is not an option, due to there not being any facilities that will accept and POA does not want patient in that type of placement." After discussing current treatment plan with patient, the attending noted that the POA was unavailable to participate in the treatment planning.

The next day, the patient reported being in abdominal pain and the test results were discussed with the POA agent who agreed with a treatment plan. On March 26, 2018, at 12:15pm, the patient was seen and medically cleared for discharge and the doctor charted wanting to discuss the discharge plan with the POA agent. Per the progress note, the proposed discharge plan included "home health and wound care and discontinuation of Fluconazole". Per the medical records received, it was noted that during the evening rounds, the attending doctor had a conversation with the patient regarding discharge options in which the patient was agreeable with the following tasks: home physical and occupational therapy, home health and family support. The POA agent was unavailable during the discussion with the patient, but there was follow-up call at 4:05pm with the POA agent. During this call the doctor explained the current situation of the patient being ready for discharge and relayed to the POA agent that there were no facilities in the city that would take the patient, that the discharge would be to the home and that the patient needed to be picked up no later than the next day. Throughout their discussion, the attending stated that the POA agent understood, and stated the discharge might occur on either Wednesday or Thursday. Also, in the course of the conversation the POA agent made a few requests for a list of nursing homes that were contacted, to try a facility outside the local community and to send test results to an outside specialist. The attending passed the requests to the case management department for follow-up. The next day during observation, the patient reported being agitated, expressed concern of the projected hospital billing and was given Benadryl. Per the records that did not help the patient, so the unit nurse gave the patient 1mg of Haldol to assist with the anxiety that was being displayed.

Per the records, the hospital was still planning to discharge the patient and the message was relayed to the POA agent as well as notification that current expenses were no longer being covered by the insurance. On March 31, 2018, at 8:00pm, the patient was discharged to the care of family members.

Interviews

Due to the time frame of the services, treatment rendered, and site visits completed, the hospital staff presented responses as an overview since those that were involved in the patient's care are no longer available.

Director of Psychiatric Services

Per the Director of Psychiatric Services, if a patient is deemed competent, they are consulted on their own medical decisions, even if there is a DPOA (Durable Power of Attorney) listed. The Director pointed out that the following form (IL462-2102) "Declaration for Mental Health Treatment", can also be completed by a patient, which outlines their mental health treatment preferences and decisions regarding their care, if they are deemed to lack capacity during their admission, even if there is DPOA. The goal is to follow what the patient desires to happen.

Per the Inpatient Manger and the Director of Psychiatric Services, who stated that if there is a (DPOA) listed and the patient is unable to make a final decision , then that person would be contacted. Also, the psychiatrist will meet with the patient to determine their level of capacity and/or competency in regard to medical decisions, and if the patient is deemed competent, all the parties would come together as a consensus to decide. If the patient is not competent and there is active and known DPOA, the decision-making abilities would fall to that person if the patient agreed.

ED Inpatient Manager

Per the ED Inpatient Manager, when the patient arrives on the unit, the patient is questioned during their admission or transfer process to see if they have an DPOA listed or an advance directive completed and if not, one can be added if the patient chooses, and it will be scanned to the patient's file.

Case Manager/Utilization Manager

On April 21, 2021, the HRA completed a follow-up virtual site visit with the Case/Utilization Manager, who was unavailable for the initial visit, along with other hospital personnel. The Case Manager/Utilization Manager stated that a patient admitted on the medical unit is assessed for decisional capacity by a case manager. If during the assessment, the patient is deemed as not having capacity, the family or individual listed on the Durable Power of Attorney Form is notified and consulted. Also, if the patient needs a psychiatric consult, after being assessed, a referral is put in place and the treatment plan is always patient centered. Per the Case Manager/Utilization Manager, the hospital for the last three years has been streamlining all their legal documents, in preparation of the merging of the hospital health systems. At this time, the hospital uses the "Power of Attorney (POA) Healthcare Form", which is located on the Illinois Department of Public Health website and the patient has to get it notarized by their personal attorney.

The HRA inquired how the medical units would know if a patient had a POA and the Case Manager/Utilization Manager stated the forms are usually uploaded in a patient's

file and the POA is listed on the medical record. Also, the Manager stated that if a patient does not have a DPOA form attached to their record and is interested in adding someone as a DPOA, a hospital case manager or social worker will complete the appropriate forms with the patient and scan into patient's file. The Case Manager/Utilization Manager stated that during an emergent life-threatening situation and there is DPOA listed, the process is for the physician to try and contact the DPOA numerous times and if unable to reach them, the physician will attempt to reach out to the secondary agent, if listed or known. While reaching out to the secondary agent if the physician is unable to make contact, they move forward to having the patient complete an affidavit or move forward with the surgery, based on which of these scenarios come first.

Director of CFMH

Per the Director, the process mentioned by the Case/Utilization Manager, is the same process for determining capacity and usage of DPOA's on the behavioral health unit. During the admission of this patient, per the records received there was psychotropic medication administered; the HRA inquired if there was a consent form that is utilized. The Director stated that currently there is not a psychotropic consent form used on the hospital's medical unit, but the hospital is working on developing a universal psychotropic medication consent form that will be used throughout the hospital.

Policy Review

The HRA conducted a policy review of the hospital's **"Advanced Directives".** The purpose of the policy is "to establish a health system-wide policy regarding patient's Advance Directive that is in compliance with the Illinois Living Will Act, the Illinois Healthcare Durable Power of Attorney Act, the Illinois Health Care Surrogate, the Illinois Hospital Licensing Act, the Illinois Mental Health Treatment Preference Declaration Act and the Federal Patient Self-Determination Act of 1990".

The policy states, "upon inpatient admission, or as soon as patient's conditions permits, all adult patients must be asked if they have an advance directive, and the hospital will comply with an advance directive to the extent permissible under the law". The policy points out that the medical personnel of the hospital "will facilitate compliance with the procedures in accordance with Illinois and federal law regarding Advance Directives". The attending physician will determine if the patient has decisional capacity to appropriately speak for themselves. During the numerous hospitalizations, the attending physician would note if the patient was able to understand and decide or if the ultimate decision is needed to be made by the Power of Attorney designee (POA). In reviewing the policy, a definition of practice is provided for the terms, "advance directive" and "decisional capacity", but there is no direction or instructions of determining "decisional capacity" by a physician. Hospital personnel reported in July 2021, that this policy was updated to include the following action: "advance directive information is highlighted on

the electronic health record". This change occurred to remind hospital personnel to make sure that the guardian or the POA agent is contacted regarding hospital admission.

While reviewing the medical records, there is a capacity evaluation that was completed during the patient's first hospitalization in which the provider notes more than once that "the *patient does have capacity to make decisions in his own best interest, he is able to hold his problems in consciousness, able to discuss consequences of refusing to go home, as well as comprehension of alternatives…."*

The HRA conducted a policy review of the hospital's **Patients' Rights and Responsibilities.** The stated purpose of the policy is "to establish a hospital policy regarding patient's rights and responsibilities." A listed patient's rights that stood out during this patient's numerous admissions was "patients and their families have the right to receive complete and current information from their attending physician communicated in terms they can understand, regarding diagnosis, treatment and prognosis, and all outcomes of care, including unexpected or adverse outcomes". This right was evident during each admission, throughout this patient's numerous admissions; the hospital ensured that the patient had capacity to understand the treatment plan and what was occurring in that moment. If the patient was not lucid or misunderstood what was occurring, the hospital personnel would attempt reach out to the DPOA agent and then return to the patient after giving time to regroup and talk with those individuals that he deemed appropriate.

Conclusion

Complaint: The patient was not given the right to refuse services or medication.

Per the Mental Health and Developmental and Disabilities Code pertaining to psychotropic medication, " an adult recipient of services or 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 or electroconvulsive therapy (405ILCS 5/2-107(a))". When a patient is under medical care, per the Medical Patient Rights Act, the patient has the right, " … to refuse any treatment to the extent permitted by law(410 ILCS 50/3(a))." Whenever there was a change to the patient's medication, the physicians noted if the patient displayed decisional capacity and understood the explanation before completing the prescription submittal and the patient at various times requested various medications from the staff (psychotropic and non-psychotropic) to address an ailment that he was experiencing and for which he wanted relief. A rights violation is **not substantiated.**

Complaint: The patient was not provided with the right to choose or use the statutory health care power of attorney agent.

The Illinois Power of Attorney Act outlines that " the agent is authorized to give consent to and authorize or refuse, to withhold or withdraw consent to any and all types of medical care, treatment, or procedures relating to the physical or mental health of the principal, including any medication program, surgical procedures, life-sustaining treatment, or provision of food and fluids for the principal (755ILCS 45/4-10(c.1)". Per the Case/Utilization Manager, the patient has a right to choose who they want involved in their care, even if there is a POA listed, and the patient is deemed to have capacity. The Illinois Power of Attorney Act states that "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 power has to act for the patient under a health care agency (755ILCS 45/4-7(a))". -While reviewing the medical records for each hospitalization, the physicians and nursing staff would discuss next steps with patient and if he did not understand, significant effort was made to contact the POA agent either via telephone calls, faxing requested information, in-person meetings that were requested by POA or impromptu meetings that occurred during patient visits. A rights violation is **not substantiated.**

Overall Suggestion

The HRA offers the following suggestions:

1) During the intake or initial assessment, once hospital personnel is informed of the patient has a guardian, POA agent and/or Advanced Directive that a copy is immediately uploaded or already part of the medical record.

2) The Illinois Power of Attorney Act does not require the notarization of POA documents, and the hospital must remove any policy/procedure that requires this.

3) For patients that have a guardian, POA agent or healthcare proxy, ensure that this information is noted and clearly accessible in the patient's medical records, specifically the communication preference and what information is to be shared. The rationale is to ensure that the healthcare proxy, POA agent or guardian is aware of medical and treatment options and the medical records reflect this interaction.

4) When developing the discharge plan, ensure the planning begins during the patient's admission with all the appropriate individuals involved, which reduces the chance of patient readmission. The rationale is that the sooner the discharge planning process begins , the more effective delivery of services and treatments will be, and the willingness and ability to provide care by the guardian or POA agent can be examined and discussed in case there needs to be a shift in service delivery.

The HRA would like to thank the staff of UW Health/SwedishAmerican in Rockford, IL for their cooperation with this investigation.

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.