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Peoria Regional Human Rights Authority
Report of Findings
Neurology Clinic of Peoria
Case #08-090-9010

The Peoria Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following complaints concerning the Neurology Clinic of Peoria:

1. The clinic did not properly counsel or educate a patient regarding appropriate cautionary safety measures for seizure patients.

2. The clinic violated confidentiality protections by disclosing an adult patient's medical information to the patient's parents without a signed release of information.

3. The clinic failed to acknowledge the patient's spouse and failed to educate the spouse on how to properly care for a seizure patient.

If found substantiated, the allegations represent violations of the Health Insurance Portability and Accountability Act (HIPAA) regulations (45 C.F.R. 164.506) and the Medical Patient Rights Act (410 ILCS 50).

The Neurology Clinic of Peoria serves approximate 3,000 to 4,000 Central Illinois patients every year.

METHODS OF INVESTIGATION

To investigate the allegations, an HRA team met with and interviewed the clinic's neurologist and office manager, examined a record, with the patient's written and witnessed consent, and reviewed clinic policies and procedures. Telephone contact was made with the patient to verify his consent to involve the HRA and to release clinic information to the HRA.

COMPLAINT STATEMENT

The complaint alleges that the confidentiality rights of an adult recipient of services were violated when the clinic contacted the recipient's parents rather than the recipient regarding treatment information. The recipient, who maintains his legal rights, had experienced an increase in seizures and had gone directly to the clinic for treatment after experiencing a seizure at work. The recipient's neurologist was unavailable at the time the recipient went to the office

and the clinic informed the recipient that the neurologist would review his record and recontact him. The clinic contacted the recipient's parents rather than the recipient with treatment recommendations. The parents reportedly did not relay the treatment recommendations to the recipient before he had a seizure in the swimming pool which resulted in a loss of oxygen for several minutes. The recipient was in a coma for a period of time and now has long-term disabilities, including a visual impairment. Upon receipt of the release, several additional complaints regarding the clinic were reported including inappropriate medication orders, inadequate medication dosages, lack of patient education, lack of acknowledgement of and education for the patient's spouse. The Authority determined that complaints related to the appropriateness and adequacy of medication was beyond the Authority's scope and expertise. The Authority did decide to include the allegations regarding spouse and patient education as part of its investigation in addition to the confidentiality issue.

FINDINGS

Interviews

The HRA began its review by obtaining the following information regarding the clinic and its services in interviews with the clinic's neurologist and office manager. Patients are initially referred to the clinic by their attending physicians. The clinic has one primary neurologist who has been at the clinic for eight years. Office hours are from 9 a.m. to 5 p.m., Monday through Friday; however, the neurologist is on-call 24 hours per day, and he sometimes shares on-call responsibilities with another physician. The clinic sees all types of neurological needs, including patients with seizure disorders.

When patients first come to the clinic, neurological needs are determined through medical tests and evaluations. For individuals with identified seizure disorders, information is provided regarding precautions to be taken related to driving, the need for supervision, etc. The information is shared verbally; recently, the clinic developed a form that provides a written explanation of precautions. If a patient's parents or spouse attends an appointment with a patient, precautions are also explained to them. For patients under the age of 18, the parents are required to be involved. Patients and their families are encouraged to ask questions and can always call the office with any questions or concerns. Referrals are also made to any available support groups such as the Parkinson's and Muscular Sclerosis support groups, which can provide additional education as well as support.

The clinic's attorney described the clinic's approach to releasing information. The attorney asserted that while release forms are available, releasing protected health information can be inferred when a patient invites others into the examining room to meet with the neurologist. The office manager reported that the accuracy of patient contact information is reviewed at every appointment; any changes are immediately recorded in the patient's record. The issue of family involvement is strictly left up to the patient as per the office manager.

Information regarding the patient in question was then discussed. The patient has been seen at the clinic since 2002 when he was 15 years of age. He was referred by his attending physician after he had repeated incidents of blank, staring spells and as an abnormal

electroencephalogram (EEG). He was diagnosed with a seizure disorder and his parents typically came to his appointments with him. Until very recently, the patient was still covered under his parents' insurance through health benefit provisions under the Consolidated Omnibus Budget Reconciliation Act (COBRA). The office manager reported that the clinic did not know that the patient married; the spouse never came to the office and the patient never reported his marital status or spouse's contact information to the clinic. The office manager stated that the spouse contacted the clinic after the patient was hospitalized and the clinic would not release information to her because they did not know of her involvement with the patient. The neurologist reported that the patient had been working and driving; however, the patient was reportedly instructed that he should not drive within six months of having a seizure. The neurologist also reported that he questioned the patient's compliance with medication. On the day in question, the neurologist stated that he needed to reach the patient because of his low Dilantin level. The only additional contact information that the clinic had was contact information for the parents which is why the parents were called. The neurologist stated that he attempted to educate the patient at all times about his seizure disorder and, in particular, about medication compliance, indicating that the patient was more compliant when he was younger. The neurologist stated that the patient is no longer a patient at the clinic.

Record Review

With consent, the HRA team examined the clinic's record on the patient beginning with his initial clinic referral. The patient first came to the clinic on February 11, 2002 when he was 15 years old; he had six episodes of blank stares that lasted 10 to 20 seconds and an EEG was abnormal. The patient was diagnosed with "…focal seizures with secondary generalized seizure." Medication and additional evaluations were ordered. In May of 2002, the patient was seen in a hospital emergency room for repeated seizures. The neurologist from the clinic saw him at the hospital and provided a hospital discharge plan that included the following instructions: schedule an EEG; "patient is not allowed to swim, climb high or drinking [sic] alcohol or driving;" parent supervision for the weekend; and, medication compliance. The record indicates that EEGs were repeated in 2003, 2004 and 2005. A Neuro Testing Report, which included an EEG, was completed in October 2007. This report states that the patient was admitted to the hospital on 08-18-07 and discharged on 08-31-07. The report states that "The patient is a 20-year-old male with a history of seizures and a subsequent anoxic brain injury due to an instance of near drowning in a swimming pool." The EEG is listed as being abnormal but improved compared to an EEG completed on 08-18-07.

The record indicates that lab levels, including levels to measure the presence of anticonvulsant medications in the patient's system, were done on a regular basis beginning in the Spring of 2002 through the first part of August 2007. The record documented that anticonvulsant medication levels were drawn at least 36 times during this approximate 5 year time frame. Levels fell outside the normal range approximately 20 times; of those 20 times, on 14 occasions, the levels are listed as being low, and on 6 occasions the levels are listed as being high. When abnormalities were listed, handwritten notes were documented on the lab reports indicating medication changes or the need for follow-up lab levels. On one report (05-06-06), when the lab levels fell within the normal range, there is a note that it is acceptable for the patient

to drive. On another report, dated 01-06-06, there is a note stating that the patient is not taking his medications.

The HRA examined the neurologist's progress notes from February 2002 through 08-03-07. It appears that the patient's parents were actively involved with the patient's care, either by being present with the patient at appointments, notifying the clinic of any new seizures or incidents, informing the clinic of the patient's insurance status, or being notified of medication changes or test results. The HRA notes that documentation of "office visits" do not always indicate the presence of a parent. The most recent family contact was noted on 08-03-07 in which it is noted that the neurologist "talked to his father. He needs to comply meds. [Check] Dilantin level in 2 wks." On the same day there is a note that the on-call neurologist informed the patient that he should not drive until he is seizure free for six months. The only releases of information in the record are from 2003 and concern the sharing of patient information for insurance purposes. The release form includes a brief statement about the purpose of the release, a signature line for the patient/guardian, and a signature date.

Also contained within the physician's notes are several notes indicating the provision of following directions or precautions:

05-02-02:	"Suggested be consistent with [medications] - have labs drawn and follow-up."
08-12-02:	"Still not Driving….No Driving until 12/02."
04-14-03:	"Ok to drive."
09-04-03:	"Lack of sleep…Needs good sleep."
11-20-03:	"Mother will make sure he is taking meds, will change dosing."
02-16-04:	A driving test was ordered.
10-05-04:	"No seizure x 6 [months] - then drive."
07-15-05:	The parent was to verify that patient was taking correct medication dosage after low lab level. "Said no driving until therapeutic level achieved."
11-03-05:	"Seizure while driving."
05-05-06:	"Dilantin level needed to be regulated before driving."
11-16-06:	"General check no complications….Driving now."
06-26-07:	"No driving for 6 months."

On 04-30-07, the neurologist completed a statement that the patient could return to work full-time with notes that the patient needs to comply with meds and fully rest at night. Another doctor wrote a note to the neurologist stating that the patient needs to be seizure free for six months, that the patient is working in a dangerous environment, and that clarification is needed. A response was provided that the patient had an approximate 11 month period without a seizure and the most recent seizure was probably related to lack of rest.

As previously indicated by the clinic, there was no formal instruction or educational sheet in the patient's record.

With regard to the patient's spouse, the HRA found no documentation that the patient was married or that the spouse should be a contact until the final note in the record dated 12-13-07 which stated the following:

> PC pt wife to leave a complaint. If [patient] had blood level 08-17-07 why was he sent home without seeing the Doctor. She repeatedly c/o [complained of] that it [sic] was not address. She repeatedly called me a liar. I informed her I could not discuss his medical History with her but I could take her complaint. She wanted it noted that [patient] never updated his HIPPA [sic] forms. [Patient] was not married at the time he was a patient of [neurologist]. She also informed me that he will not be seeing [neurologist] anymore.

Clinic Policies and Forms

The HRA examined the clinic's privacy notice. The clinic has two versions: a shortened version provides a summary of the clinic's privacy requirements and a more detailed version of the same notice that is made available should patients want more information or have questions. The longer version is also placed on the counter in a protective, clear folder for patient perusal when checking in. The HRA noted that neither form includes a date in which the notice was developed. The shortened privacy notice explains patient rights and requires a patient signature and signature date. Both versions assert the patient's right to confidentiality. Both versions state that the clinic may make disclosures with and/or without authorization to: "Business associates, notification, communication with family, incidental uses and disclosure." The detailed version expands on this by stating the following:

> We may use or disclose to a family member, other relative, close personal friend or any other person you identify, health information related to those person involvement or payment related to your care…There are some services provided through contracts with business associates which are vendors, professionals and other who perform some treatment payment or health care operations function on our behalf or who otherwise provide services and have access to or use your protected medical information….When these services are contracted your medical information may be disclose [sic] to our business associates so that they can perform the job we have asked them to do….We may use or disclose medical information about you without your prior authorization….To Public Health ….to a governmental authority if we reasonably believe you are a victim of abuse, neglect, or domestic violence…To Health oversight inspections….

The lengthier version also states that written authorization is required to disclose medical information but then lists the following specific circumstances under which written authorization is required: insurance, attorneys for litigation, marketing, and "highly confidential situations" such as HIV or sexual assault.

The HRA examined two forms. One form allows the patient and clinic to identify individuals with whom the clinic may discuss the patient's health or payment information. There is no signature line related to this section. Instead, there is a separate section that requires the patient to initial and date a statement if the patient objects to sharing health or payment information with "any family member, other relative, or close personal friend." The form also allows the patient to identify acceptable methods in which the clinic can contact the patient (e.g. home phone, answering machine, cell phone, other). A separate form is an acknowledgement of receipt of the privacy notice to be signed and dated by the patient and a witness. There are no dates on either form as to when they were developed.

The newly developed patient checklist for seizure safety allows the neurologist to check off instructions for the patient to follow, including the following: no driving; no swimming; no swimming without supervision; no bathing without supervision; no climbing high; no alcohol; must comply with medications; and, must get 8 hours of sleep. There is no indication that a copy of the form is kept or the date that the form was created. There are also no patient or physician signature lines.

MANDATES

Regulations that govern the privacy of protected health information (45 C.F.R. 164.502) state that health care information may not be disclosed except in certain, specified situations. Information can be disclosed to the patient, to a business associate as long as the associate safeguards the information and to personal representatives in certain situations. With regard to adults and emancipated minors, a personal representative must be someone authorized to represent the adult or emancipated minor under applicable law (e.g guardian) the health care agency can disclose information. The parent of an unemancipated minor is to be treated as a personal representative with respect to protected health care information unless the minor consents or can consent to health care and no other consent is required or the parent/guardian agrees to a confidentiality agreement between the minor and the health care provider.

Regulations further state, in Section 164.508, that authorization is generally required to disclose information. Examples provided include psychotherapy notes and marketing. A valid authorization is to include certain core elements such as a description of the information to be disclosed, the name of the person authorized to make the disclosure, the name of the person/entity to whom the disclosure is to be made, the disclosure purpose, an expiration date, a signature line/date, a statement regarding the right to revoke the authorization, the consequences for refusing to sign, and whether or not information can be redisclosed. The authorization is to be written in plain, understandable language and a copy is to be provided to the individual.

Regulations also specify, in Section 164.510, circumstances in which an individual should be notified in advance of a disclosure to provide the opportunity for the individual to agree or object to the disclosure. Examples include listing an individual's name in a health care facility directory, emergency circumstances, and "…for involvement in the individual's care and notification purposes." This section states that a health care provider can disclose information to a family member or close personal friend or other individual identified by the individual if the individual has health care decisional capacity and is present for the disclosure and agrees with the disclosure and if after providing the opportunity to object to the disclosure, does not object. This section also allows the health care provider to disclose information if it:

> Reasonably infers from the circumstances, based on the exercise of professional judgment, that the individual does not object to the disclosure….If the individual is not present, or the opportunity to agree or object to the use or disclosure cannot practicably be provided because of the individual's incapacity or an emergency circumstance, the covered entity may, in the exercise of professional judgment, determine whether the disclosure is in the best interests of the individual and, if so, disclose only the protected

> health information that is directly relevant to the person's involvement with the individual's health care. A covered entity may use professional judgment and its experience with common practice to make reasonable inferences of the individual's best interest in allowing a person to act on behalf of the individual to pick up filled prescriptions, medical supplies, X-rays, or other similar forms of protected health information.

Section 164.152 describes situations for which an authorization or opportunity to agree or object is not required. These circumstances include the following: disclosures required by law; disclosures for public health purposes; disclosures related to abuse/neglect; disclosures for health oversight activities; disclosures for judicial and administrative proceedings; disclosures for law enforcement purposes; disclosures about decedents to coroners/funeral directors; disclosures for research purposes; disclosures to avert serious threats to health or safety; disclosure for specialized government functions; and, disclosures for workers' compensation.

Section 164.520 describes the notice of privacy practices, including required elements. The notice must contain a description and an example of the types of disclosures permitted for treatment, payment and health care operations, a description of each purpose for which information can be disclosed without written authorization, a statement that other disclosures require written authorization, a statement of the individual's rights (right to request restrictions on disclosures, right to inspect and copy information, the right to amend information, the right to receive an accounting of disclosures, a right to obtain a paper copy of the notice), a statement that the provider is to maintain the privacy of individuals, a statement that the provider to abide by the notice, a statement regarding changes in the notice, a statement regarding filing complaints, contact information for further questions, and an effective date.

The Medical Patient Rights Act (410 ILCS 50) identifies specific rights for patients receiving medical care. Included in these rights are the following:

> The right of each patient to care consistent with sound nursing and medical practices, to be informed of the name of the physician responsible for coordinating his or her care, to receive information concerning his or her condition and proposed treatment, to refuse any treatment to the extent permitted by law, and to privacy and confidentiality of records except as otherwise provided by law.

CONCLUSIONS

Complaint #1: The clinic did not properly counsel or educate a patient regarding appropriate cautionary safety measures for seizure patients.

The Medical Patient Rights Act states that a patient is entitled to receive information about his condition.

The clinic neurologist reported that educational information is routinely shared with patients during office visits. The HRA found documentation in the record of a patient that the neurologist did discuss precautions with the patient related to driving, sleeping, and medication

compliance although no formal educational information was provided to the patient. The clinic recently developed a seizure safety checklist that can be provided to seizure patients.

Based on the documented evidence that the neurologist shared precautions with the patient, the HRA does not substantiate the allegation that the clinic did not properly counsel or educate a patient regarding seizure precautions.

The HRA does offer the following suggestion for consideration:

1. On the newly developed seizure checklist, consider adding signature lines and dates for the patient and physician.

2. Besides providing the patient with a copy of the safety checklist, keep a copy of the checklist in the patient's file.

3. Reissue the checklist on a periodic basis.

Complaint #2: The clinic violated confidentiality protections by disclosing an adult patient's medical information to the patient's parents without a signed release of information.

The Medical Patient Rights Act guarantees the privacy and confidentiality of patient records. Regulations that govern the privacy of protected health information (45 C.F.R. 164) indicate in section 164.502 that health care providers can disclose protected health information to individuals authorized by law to represent a patient (e.g. guardian, agent in a health care power of attorney). Section 164.508 specifies that a written authorization is required in most other situations and identifies the elements to be contained in a release form. And, section 164.510 describes situations in which a patient should have an advance opportunity to agree to or object to information disclosure, including sharing information with a family member; however, the provider can infer that a patient does not object based on circumstances. Section 164.152 describes situations in which written consent and advance notice are not required in order for the provider to disclose information, such as for abuse reporting, judicial proceedings, for health and safety purposes, etc.

The neurologist reported and the record documents that the patient's parents in this case were actively involved in the patient's treatment. The parents attended appointments with the patient, notified the neurologist when the patient was having problems with seizures and handled arrangements for lab levels and other tests. Although the patient was an adult and the parents were not considered the patient's legal representative, the HRA contends that disclosure could reasonably be inferred as allowed in privacy protections based on the past and ongoing interactions between the clinic and the parents. There was no evidence that the patient objected to the parent's involvement. Therefore, the HRA does not substantiate this allegation.

The HRA does offer the following suggestions for the clinic's consideration:

1. Although regulations allow for the provider to infer that the patient would not object to certain disclosures, the general standard for the regulations state, and best practices with regard to privacy and confidentiality indicate, the use of written release forms in order to disclose information to anyone other than the patient, a legal representative, or those entities or situations in which information can be released without authorization. The HRA suggests that, when a minor patient becomes an adult, that written authorization be secured before disclosing information to the patient's parents.

2. The one authorization form examined in the patient's record did not appear to meet the requirements set forth in privacy regulations. Many elements were missing, including to whom the information is to be disclosed, the right to revoke the authorization, expiration date, the consequences for not signing the release, etc. The HRA suggests that the clinic update its authorization form to ensure compliance with mandates. Ensure that the date the form was created is listed on the form.

3. The privacy notices do not appear to be consistent with regulatory requirements. Some information does not appear to be accurate and some required information is missing. The HRA suggests that the clinic review its current notices for accuracy perhaps contacting another health care provider for a sample.

4. When another individual is at an office visit with a patient, document that person's presence and the person's relationship to the patient in the office visit notes.

Complaint #3: The clinic failed to acknowledge the patient's spouse and failed to educate the spouse on how to properly care for a seizure patient.

The HRA found no evidence that the clinic had information of the patient's marriage or contact information for the spouse. There was no written authorization for the clinic to disclose information to the spouse. There was no evidence that the spouse went with the patient to any appointments that would allow the clinic to infer that information could be disclosed to the spouse. The clinic stated that it routinely updates patient information, including contact information although the HRA could not confirm or deny this. Based on the documented evidence, the HRA does not substantiate the allegation. The HRA does offer the following suggestion:

1. Given the emergency situations that can sometimes leave neurological patients incapacitated, ensure that contact information is routinely updated as reported to the Authority.

The HRA acknowledges the full cooperation of the clinic during the course of its investigation.