Access to Health Information: It Takes a Village

Save to myBoK

By Mary Butler

Obtaining access to one's written or electronic medical records in a timely manner is one of the guarantees listed in AHIMA's "Consumer Health Information Bill of Rights." Yet, for one consumer, Amanda Michelle Jones, MS, AM, being on a first-name basis with medical records department staff is the quickest and most reliable way of ensuring she gets copies of her records when she needs them for upcoming appointments.

Jones, a social worker, has had multiple new diagnoses for chronic conditions since moving to Chicago in 2011 to start her PhD program, and has—unfortunately—been in several car accidents requiring surgeries and physical therapy in that same time span. In her presentation at the 2015 Leadership Symposium in Chicago this past July, Jones shared some of her tremendously frustrating experiences with collecting records from her many physician appointments, surgeries, emergency department visits, lab work, imaging, and other diagnostic test results.

Since the symposium, Jones has continued to hit roadblocks in the management of her own care—particularly when it comes to facilitating the sharing of records among several of her providers, she said in a follow-up interview with the *Journal*. Vera Rulon, MS, RHIT, FAHIMA, FACMImimi, director, external medical communications at Pfizer , who co-presented with Jones at the Symposium, worked closely with AHIMA officials in developing the Consumer Health Information Bill of Rights. She also spoke with the *Journal* to offer her HIM perspective on Jones' challenges.

Incompatible EHRs

Like many savvy healthcare consumers, Jones thought that the fact that the hospitals where she most frequently sought treatment all had electronic health records (EHRs) would mean they would be easier to collect. What's more, she assumed that since three of her providers had the same EHR vendor, that those providers would be able to send and receive records amongst themselves. Neither of these assumptions were true. And in several cases, clinicians within the same hospital frequently were unable to access Jones' records from previous visits.

For example, Jones was being worked up for chronic pelvic pain (which eventually resulted in a diagnosis of endometriosis) and had a slew of labs and diagnostic tests, as well as pregnancy and sexually transmitted disease testing, done at the hospital on her university campus. However, when she landed in the emergency room (ER) at the same hospital for acute pelvic pain, the clinical staff had no record of these tests, which had been done just a few weeks earlier. When the ER staff wanted to repeat these tests, Jones declined since, as a student, she couldn't afford redundant tests.

Lack of interoperable systems may account for the bulk of Jones' problems with her records, but Rulon says that in such scenarios, the patient has a role to play, too..

"Interoperability is key but alone, it may not solve the problem," Rulon says. "Patient education and additional tools that can help make it easy for them to coordinate their information and their care are also paramount, and also working on cultural issues in provider based settings to further improve patient provider communication."

In the absence of interoperable EHRs, Jones has taken matters, literally, into her own hands by printing up pertinent test results and physician notes and bringing them in person when she goes to appointments. If she doesn't have time to do that, she brings up her EHR portals on her iPad so doctors can glance through her records that way. She also collects what electronic records she can with a Box.com account.

"It's like having a whole other class and a half—organizing my records before an appointment," Jones says.

And she's not kidding. During one quarter of grad school, she had between three and six doctors appointments per week, every week, except for two weeks in one quarter.

Rulon says chronic conditions, like the kind Jones deals with, have long been a challenge for both providers and patients.

"In looking at research over time for both caregivers and care recipients, care coordination is often in the top categories of unmet informational needs. Many standard setting organizations are looking at innovative ways to address this, such as the Workgroup for Electronic Data Interchange's Care Coordination Workgroup. If we can address medication management as a start, then move on to ensuring that additional pieces of information are made available i.e., various test results, clinical and administrative data, etc., over time we may solve for this," Rulon says.

Devising Workarounds

Because Jones' health is constantly in flux and because specialists often refer her to another specialist, it's important for her to print out and take previous test results with her to a new doctor. However, sometimes those appointments are set without enough time for the tests to be transmitted from one doctor to another. Jones says most of the internal policies in the hospitals she's been to are required to take action on a release of information request within 30 days, but those providers tell her that a backlog means it'll likely take six weeks.

In some of these cases, Jones has resorted to a charm offensive, chatting up medical records staff so they get to know her. As a result, she says, she's been able to get staff to "move mountains" to get her records where they need to be.

Sharing imaging amongst physicians has big one of the biggest stressors for Jones. As a backup plan, she's used her smartphone to take pictures of X-rays and CT scans because she knows the films won't make it in time, or if she's afraid she won't get her CD of images back from a doctor.

Jones also uses her chiropractor as a home base of sorts for her medical history. When she gets a new diagnosis or diagnostics completed, she'll take the results to the chiropractor who likes to keep an eye on her case. He stores paper and digital records for her. She's also learned that records are transferred from one place to another more quickly when a doctor's office makes the request for old records. On the other hand, she's also had physicians tell her that the hospitals that employ them can't be trusted to send or receive records, and tell Jones that she should manage the transfer of records on her own.

These experiences have left Jones feeling like she needs to coach people in similar situations.

"When I meet people struggling with stuff, I say 'Let me tell you what I've learned. I don't want to scare you, but I'd much rather have you go in prepared for the experience than to go into it blindly, not knowing what to do," Jones said.

Rulon echoes this sentiment.

"I felt for Amanda Michelle as I've heard similar stories over time. When I heard her story, I also saw an opportunity to help people like Amanda Michelle, and more so, those who are not as knowledgeable on navigating the healthcare system."

You can read more about Jones' at her blog, at http://www.amandamichellejones.com/.

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