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Geri Amori: Hello, everyone, and welcome to *Healthcare Perspectives 360*, a series dedicated to exploring contemporary healthcare issues from multiple perspectives.

I am your host, Geri Amori. And today I'm talking with Danielle Ofri, MD, Stacy Nigliazzo, RN, and medical defense attorney Jake Kocienda. Welcome, everyone.

In 2021, the 21st Century Cures Act, also known as OpenNotes, resulted in patients having rapid access to their medical information, sometimes before their doctor sees it, and has made understanding the implications of medical information very complicated for patients. So, let's talk about that today. Dr. Ofri, how has OpenNotes changed your relationship with your patients about test results?

Danielle Ofri, MD: Well see, it's not really limited to test results. I mean, what the OpenNotes really changed most, I think, practically, is our notes, that now our patients see our notes in real time, in addition to their test results. And that's where I see the biggest change, that I've changed how I write. And once I know someone's reading my notes—for better or for worse—I have limited the detail I put in my notes.

So, for example, when I might have described, you know, in a patient who has depression, for example, we will often comment on their physical appearance because someone who is disheveled appearing is clearly in a worse state than someone who is well groomed. And we'll use those terms. However, patients find that very insulting to read that someone's commenting on appearance, even if it's for a clinical reason. We've stopped doing that.

The other thing I've stopped doing is elaborating a differential diagnosis. So if the patient comes in and says I'm tired, that can be many things and that's a differential. That could be, you know, didn't get enough sleep all the way to significant cancer. In the old days, I might write out here's my list of 17 possibilities, or maybe not that many. But now I won't do that because I find that patients if they see the word cancer will freak out.

It also opens up too many cans of worms. And so, I've limited my note taking to really more about oh, here's the plan. And that's really a step back, I would say, in terms of the value of a note. We want to see explicated clinical reasoning. And it's not just me. I think everyone I've spoken to has really limited what they write.

On the plus side, I think it's good for patients to be able to see their notes and see their results. They own the chart, it's their information. But I think it would be helpful if we had some kind of filter—be that a pause or, for example, a clinical person, an RN, or a PA—available to help interpret the notes and the test results because it can be very confusing.

And I'll just add one last note about test results. You know, it comes out as a firehose. And so, you take a CBC, a complete blood count, which has about 25 values listed, only probably 3 of which we actually look at. The rest are generated automatically. But if any one of them is 0.0001% out of the normal range, it will have the big red flag, abnormal, as big as if you had a

significant thing and there's no subtlety, and the patients will suddenly get in a panic, oh my gosh, am I dying? Do I have cancer? And we get a lot of panicked calls and messages about these very insignificant abnormalities.

Amori: Right. Well, you know, as a risk management professional, what you were saying about changing the way you write your notes and sort of leaving out more information about the differential kind of hits me. I guess I'd like to go to Jake and ask do you have a reaction at all to what Dr. Ofri is saying in terms of the defensibility of, you know, records?

Jake Kocienda, JD: I absolutely do. And let me just preface with a little explanation of why this is so concerning to me, as a defense medical malpractice attorney. It's well understood that most medical malpractice cases generate and start because of poor patient reception of the situation. Unreasonable or wrong expectations of a situation or their perception. It doesn't mean bad medical care, but that's what walks them down the street to an attorney to find out if something happened.

Unfortunately, I think the OpenNotes creates that in spades. And let me explain why. And a lot of it has to do with exactly what Dr. Ofri said but translated from a patient's perspective or, in my case, plaintiff's perspective. They now have, as mentioned, this firehose of information. Now, patients are going to react to it in different ways. Some are going to be overwhelmed and just wait for the clinician to explain it and make heads or tails of it all.

But a lot of them aren't. A lot of them are going to go open up old Dr. Google and start looking into this stuff on their own. They're going to jump the gun. They're going to try to worry about things that are a problem in their mind that a clinician will absolutely not care about or see as reasonable or not a concern.

As a result of that, they're going to expect things that perhaps clinicians will not be willing or would have ever provided. For example, chasing down every abnormal lab value. Patients might simply say this is abnormal, this is high, this level's low, and the clinician can explain that's not a problem, we're not concerned, but the patient wants it chased down.

There's going to be, I think, a potential for increased, you know, inefficient medical care because patients are going to demand care, testing, diagnoses, things that a clinician readily within their training knows not to bother with or pursue. There's going to be a catch-22/Monday morning quarterbacking going on here where, "See doctor, I said this was the problem. You didn't follow through, now I'm in trouble. And, you see, you should have listened to me."

Unreasonable expectation, completely reasonable under the standard of care not to pursue it. Patients are going to be now unhappy when they wouldn't even have known it before. It's a dangerous thing sometimes to have too much information when you don't have enough.

It's the same kind of thing and, obviously, maybe for some people more important, but if you brought your car into a garage to get fixed, you don't know what the heck they're doing. You just know it starts and runs when you drive it away. Do you really need to know all the details of what they did to get to the bottom of the problem?

You know, I know it's our human bodies and everyone wants to know, but there's a certain similarity in the sense that if you have to watch the sausage being made, you're going to be upset about some things simply because you don't understand, within the broader perspective, how all this matters.

So I see this as a problem and in the future leading to more lawsuits, or at least leading to more complaints, whether it be in the Department of Public Health or lawsuits, because patients are going to be unsatisfied. And they're certainly going to be blaming clinicians for not explaining things well, jumping the gun, and not waiting for clinicians to put them in perspective but also trust them, believe the clinicians when they do put it in perspective.

Amori: So, that makes sense from a legal perspective, which, of course, you know, as a risk manager I would think about. But on the other hand, I also really understand what Danielle is saying about you have to be careful. Not all patients are going to, you know, they're going to get really upset about little things that aren't really relevant. Stacy, have you seen patients looking at their records or getting information before the clinician has a chance to really explain it to them and getting upset? Or have you noticed that at all from a patient perspective?

Stacy Nigliazzo, RN: Well again, my experience is exclusive to the inpatient hospital, and I have not experienced patients who are currently admitted in acute care facilities accessing their healthcare information, notes, lab results, or otherwise in real time, which I think is a very good thing. But if we did start to see that happening, we thankfully already have a mechanism in place, which Dr. Ofri alluded to, which was the whole idea of having someone there, sort of a navigator who can be available to help patients interpret and discuss this data, help them manage it before the physician has, or a process I should say, before the physician has a chance to talk with them.

We do have navigators at the hospital where I presently work on every floor and they're nurses primarily, who if the patient has a concern, they go in and they address it. They notify the care team, the nurses at the bedside, and the physicians as well, get everyone on the same page. And I think that that considered collaborative response, providing assurances for the current plan of care, engaging everyone at the right time, really is the key to addressing this issue.

Amori: Danielle?

Ofri: I would push back to Jake a little bit. I think that we have to be careful about not leaning toward sort of the paternalistic, you know, well we know best, you don't need to know the details. I mean, as the patient, all patients, I don't want that from my doctor. Now I may not want it all in the moment and I think I don't want to discover my cancer on MyChart. I want my clinician to call me or see me about that. But if I get my blood test, I want to see what they write. You know, the information that they have I want to know. And the same with my car mechanic.

Now, I can choose to say I don't want to know. It's my option. I don't have to. And I'll often ask patients how much do you want to know? And some patients don't want to know, and that's fine. But if they do want to know, I think it should all be there.

The problem is that we then sort of dump it on the clinician to then clean up the mess after that. And that is the 600 emails about the chloride level that is 0.01 off that someone's convinced they're going to die of multiple sclerosis. So, what we haven't done is institute really a system in place, as Stacy was alluding to, a navigator or a way of helping patients, you know, sift through this mess. And also, to distinguish it's different to release a pathology report instantly, as opposed to your CBC.

And I think we can have some, you know, I don't think it's paternalistic to have a three-day pause, for example. Because before I call the patient about their cancer, I want to call the oncologist, set up the plan. I don't want to call them and say well, I don't know what to do. I want to have a chance to review the CAT scan. So I don't think it's harmful to have a small pause, but I think all of it should eventually be at the patient's disposal if they should want to look at the, you know, the sausage.

Amori: Jake, you want to say something about that I see.

Kocienda: Yeah, I absolutely agree with Dr. Ofri. I don't mean to sound that I'm suggesting paternalistic approach to this, but I think what she mentioned is exactly sort of the thought I had, which is the open sort of here's everything, go look at it and no discussion, no explanation is the danger. A pause, as Dr. Ofri mentioned, before information's delivered so that the doctor or the clinician can gather and figure out a strategy and a plan of how to deliver the information I think is absolutely appropriate.

You know, the idea is that it has to be immediately accessible to the patient just as immediately accessible to the clinician I think is a mistake. I really do. They can have access. In fact, if you think about it, they already do have access under the HIPAA regulations. They have an entitlement to access of their records. They have to affirmatively request that under HIPAA, but they do have access to that. What the Cures Act does is no longer do you have to request it, it's automatic, and it's just open book whenever you want it. And even then, before technology, you would have had to go down to the office. If this was enacted 30 years ago, you have to go get those records.

Now because of technology, it's all immediately available, and that's the danger is that, you know, clinicians go through lots of education, training through residency, fellowships, lots of experience to take this raw data information and process it and deliver the medical care based on it, whether it be advice, explanation, what have you.

What this does, it takes it all away and, you know, when I mentioned Dr. Google, that's exactly the problem, is that the clinicians are now going to go out, rather, I'm sorry, the patients are now going to go, many of them, and try to figure all this out on their own, forgetting the fact that the clinicians are there to guide them through the process.

Some will not trust their clinician simply because that's some people's human nature. Some will defer to them. But without collaboration, it's a danger and that I think is the problem, is that the act was enacted and just unleashed on the public with no education and no real understanding of what they're getting themselves into.

Amori: So, you know, as a patient, I was in the ED with my spouse a couple of months ago, and I was getting his results before anybody came in to talk to us about it. Stacy, have you found that that's what's happening with patients and families, and do you see it different inpatient/outpatient? Or what would you like to say about all of this?

Nigliazzo: Well, I would just say that I agree. That as far as information, your private healthcare information is concerned, patients do have every right to that, and I do believe the door should be open. But I believe that clinicians bear the responsibility, as Jake and Dr. Ofri both said, to package it appropriately and to make sure that it's delivered responsibly.

Also think about whether the patient's getting potentially catastrophic news. As Dr. Ofri said, the word cancer or positive results for, you know, for an STD or even for something, you know, even monkeypox, you know, here recently. That could cause a lot of stress and trauma. And, you know, if no one is there when the patient receives this news to engage resources for them on the backend, we could be doing more harm than good.

So, I think it's absolutely important that they have access to this information, but I believe it should be after the clinician has a chance to discuss it with them and has approved that it should be available.

Amori: Okay, so Dr. Ofri, what do you tell your patients to do if they happen to go on MyChart and see a result that is disturbing before you've had a chance to really talk with them? How do you work with your patients on that?

Ofri: Well, one thing, if you want to really set the stage well, that takes quite a bit of time. And I will be honest that I don't have that. In our short visit, we're already dealing with their diabetes, hypertension, cholesterol, cancer, depression, heart failure. I can barely get all of that in there. So, to take more time to discuss the ins and outs of MyChart is simply beyond what I can reasonably do. So it doesn't feel like a fair burden.

What I would say is if there's anything that's serious, I will call you. I always try to put that in. And if I have time, I'll say sometimes there's some abnormal things that aren't important, but I often don't have time to go and explain false negatives, false positives. It's really quite, quite detailed. But I do think it should all be there for patients. They don't have to request it; it should be there.

They can choose not to look at it, that's fine. And it shouldn't just depend on us getting around to it. So maybe there's an amount time, three days, the same way we have with MyChart messages. The patients get a notice, please expect three business days before a response. That's reasonable. And we could do the same thing with results. But then we have to give clinicians dedicated time to do that, to now squeeze that in in your invisible lunch hour, after hours, or weekends, which is what happens because there's no dedicated time. But this is patient care.

You know, like telemedicine, this is another form of care. We get the A1C, we call and adjust the diabetes medicines. That's real care. That takes time. So I think if our system wants to embrace

this open information, then we embrace dedicated time for clinicians to then be calling patients or messaging with them to talk about the ramifications of their results.

Amori: That makes a lot of sense. And you're right, it's an unfair burden. And so, from an attorney's perspective, if you were telling people, doctors, what would you say to them about how...what to say? Do you think what Dr. Ofri is saying is reasonable?

Kocienda: I do. I do think it's reasonable. The time commitments and the burdens that are placed on the clinicians is just increasing. Every time there is an enactment of a law, it seems to always be placing some burden on the medical field and the medical community rather than on patients, more and more.

And the problem with that is, as Dr. Ofri mentioned, is you just don't have time to get to it all. But I think in this context, there is a need for some education of patients to how to use this new tool, the OpenNotes, and the patient portals that are created. It doesn't have to be from a clinician though. You know, an MA or maybe someone can go in and when they institute the new program, give a little bit of an education, maybe some pamphlets or something, but an education to the patients so that they can understand and sort of get ahead of this issue.

You're going to get this raw data, you're going to get these lab results, imaging results, what have you, please understand the context. And that's what the clinician's going to do, is put this in perspective. Don't jump the gun, don't get excited, don't whatever. You will get notified. These types of things could help maybe water down the negative effects and bolster the positive impact of them being able...patients being able to access their own data.

Amori: That makes sense. And, Stacy, from the nurse's perspective, if an impatient family member gets a hold of that, opens the MyChart and has access and reads things and starts asking nurses well what about this, what about this, what do you recommend nurses say?

Nigliazzo: So, yes. And the answer to that always is let me look and see what you're looking at, so I understand what we're seeing. Okay, so let me speak with your physician, let me get someone in here who can explain to you what this means, and in the meantime, I want to provide assurance we are going to take care of you. Give me just a moment to collaborate. And hopefully you've already built trust with this family. And if they're not going to allow you that moment, if they're so upset at this point that you're not going to be able to leave the room, that's when you engage the navigator to come and guide that talk while you're working behind the scenes to assemble a collaborative team here, let's talk about this.

Amori: Fabulous. And I'm sure that many of the nurse in our audience are like thank you. Because that's really a pickle for them when families are doing that. So, our classic question, as we close for today: what is the one thing you would like our audience, both healthcare professionals and lay people alike, to take away from this discussion today? And let's start with you, Dr. Ofri.

Ofri: So I think that philosophically patients own the medical charts, and they have the right to all the information, everything written there, there should be nothing, unless there's a narrow

window where it might cause patient harm in some rare circumstances. But I think that we then also have to put in place a system to help patients navigate this and not simply expect the clinicians to figure this out on a Saturday night of who do we call. And that would include some resources, be they a nurse navigator or dedicated time for physicians to go through these charts and to call patients. So it's a great tool, but it can't exist on its own as a firehouse.

Amori: Excellent. Thank you so much. Stacy, what about you? What would be your point for today?

Nigliazzo: Well, I agree that patients have an absolute right to their private health information. But it must be delivered responsibly. The answer is always a considered collaborative response, redirecting, and providing assurances for the current plan of care.

Amori: Thank you. And Jake.

Kocienda: I think it's important for those listening to keep in mind that patients do have a right to their access to their records. And, in fact, they did long before the Cures Act. I think the Cures Act is more of a technological rule to allow instantaneous access, which is fraught with danger in this immediate instant gratification world. And I think that, like any technology, it has to be tempered and put in the right perspective. And the best way to do that is educating the patients to understand how to assimilate this information and what not to do with it, so that they benefit just as much as the lawyer...or the lawmakers wanted them to. Rather than, as Dr. Ofri mentioned, and to coin her phrase, a firehose of information, which is just going to cause them to drown in it.

Amori: Thank you. Well, thanks so much for joining us today and a special thanks to our panelists for this very energetic conversation, shall I say. It was really good and brought many different perspectives.

So until next time, this is *Healthcare Perspectives 360*.

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