OpenNotes/University of Iowa Health Care
Mental Health Podcast TRANSCRIPT

Steve O'Neill: This is Steve O'Neill I'm the Mental Health Specialist at the OpenNotes program, working on the dissemination of open notes in the behavioral and mental health arena across the country. I'm also a clinical social worker and manager overseeing many of the behavioral and mental programs at Beth Israel Deaconess Medical Center in Boston. That's where I helped guide the implementation of open therapy notes in 2014.

And today I'd like to welcome from University of Iowa Health Care, Chief Medical Information Officer, Dr. Maia Hightower, and psychiatrist Dr. Alexander Thompson, who is the Associate Vice Chair for Clinical Affairs in the Department of Psychiatry and a Physician Informatics Officer. We're talking about the environment at Iowa and how that supports note sharing across all settings, including courageously, in mental health care.

Maia and Alex, welcome.

Maia Hightower: Thank you

Steve: What might be helpful is to talk a bit about your system there in Iowa. You're the main medical system, really for the state of Iowa. It looked to me you have 14,000 employees, somewhere in that ballpark, so it's a very big system.

Maia: So we are the only academic medical center in the state of Iowa. We have a 734 bed hospital, which is a combination of both an adult and children's hospital. We're very proud of our position the University of Iowa and we provide care for the entire state.

Steve: And the University of Iowa was one of the very early implementers of OpenNotes, of opening up their notes to patients. Maia can you tell me a little bit about the decision to open the notes there. How it was received by the clinicians and how it was received by your patients.

Maia: Sure, the decision to open notes to patients occurred back in June of 2010 and that was before I came to the institution. It was a big bang approach, where access to ED, ambulatory and inpatient were made available to patients. The story goes is that there was some grumbling at the time. By the time I joined the University of Iowa in 2015, I have heard very little. I mean it's just part of the day to day operations.

Alex Thompson: I'll speak to this a little bit. This is Alex. We have extensive behavioral health services here. We have a child psychiatry inpatient unit, two different adult psychiatry inpatient units, a geriatric psychiatry unit. One of the adult units has a specialty eating disorders service. We have a special intellectual disabilities service and then we have medical psychiatry unit. We have a partial hospital program for people with mood disorders and then we have a partial hospital program for people with dual psychiatric and substance use disorders and then extensive outpatient services.

I did my internship here in 2002, and it was before Epic had gone live here, and I was impressed at the time, and maybe I didn't know any better because I was an intern, that all of our behavioral health records at that time were open to everybody, so when I would complete notes on the inpatient unit, the

family medicine providers could see that and see those notes. And I guess I didn't realize the cultural impact of that or the impact that the culture had on doing that until I went to a respected east coast institution for years three through four, and all of the behavioral health notes were sequestered in a special part of the hospital on paper and were inaccessible to anybody, but the behavioral health services. I mean hidden to a degree that I thought was peculiar, stigmatizing and just kind of a pain also because you had trouble finding out what was going on unless you had secret access to the clerks who kept these things like some sort of secret vault at the national library.

Maia: Yeah and that kind of, sort of hints at the history of the electronic medical record here at the University of Iowa. They had a homegrown system as early as the 1980s. We were an early Epic customer as well when we went from our homegrown solution to Epic in 2008/9 timeframe. So, we've been on electronic medical records for a long time, which kind of changes where the barriers of entry are and the barriers to access are.

Steve: I think both of you are speaking a little bit to the cultural aspects of what allows a system to think about opening up their notes in a much more transparent way and Alex, your experience of the east coast having the notes be sequestered off from the rest of the system as opposed to Maia what you're describing as a truly integrated care system where everyone's notes are open so that you can learn from each other so you know what's going on so that you can complement the care. And I wonder how that affected your staff's view of making the leap to opening them up to your patient population.

Maia: I would imagine it definitely decreased that barrier, because it was already open to each other. If an institution first has to open up to each other and then open up to patients, then there's two culture shifts that are required versus just one. But again this has been a feature hear at University of Iowa for so long that it's hard for us to recognize the challenges that other institutions that have different cultural and historical factors to deal with are facing.

Steve: And Alex, your thoughts? Anything to add?

Alex: It's not really a discussion point. It's just something that's done, and it makes sense. So we just advance and can talk about other important things besides sequestering all this information. So it's very cool to be in an institution where we're just, just kind of get over it, and so we can talk more about how the documentation's appropriate. Make sure what we're putting there is something that we're comfortable with them seeing, and how do we use it then to facilitate how we're going to better take care of them. And that's what been cool to listen to providers here talk about.

Steve: I like what Alex said about using the note to facilitate clinicians taking better care of patients, and I think that goes both ways. I think patients can use the note to feel understood, to be more engaged, and to facilitate taking better care of themselves. Take a listen Stacey here.

Stacey: For me I go back to my OpenNotes all the time. I need to remember what is it that we talked about. What is it that we're going to talk about at the next session. But, I'm not going to lie to you, reading it, it's a hard read for me, some of it, to sit there and review what Lissa and I talked about and for me to go to the place of, gosh, I can't believe I'm that person, you know. But, I don't let it get me down and I say I am that person and she's going to help me get through these obstacles.

Steve: So much of the push back to open therapy notes is the worry that patients won't be able to handle the information in their notes, but this patient's experience mirrors much of what I've seen with my own patients, that it's not one size fits all, but if the notes reflect what was discussed in the session, even if that information is difficult to take in, the majority of patients benefit from an improved understanding that comes from reading their notes or in addressing differing perspectives.

When Marsha Linehan came out with Dialectical Behavioral Therapy, that was predicated upon actually openly discussing with the patient what their diagnosis is and previous to that therapists had been very worried about having those discussions and what was found was that when the patient population when they realized, oh that's the condition I have they were better prepared to understand what it was and could actually make advances in their therapy, and their work, and in their lives in mitigating some of the issues around it. So it really was a terrific tool. So it's, in some ways, OpenNotes is a little bit of a variation on that in my experience. I don't know if that's true for you.

Alex: People who you might think are worried about having borderline personality disorder in a note, and when you have a national expert talking about how, oh I like having in the note. It's something I talk to the patients about quite a bit, and so it being there facilitates a discussion about why this diagnosis is there and how were using it as a point to move forward in care. It's been really, it's cool to see.

Steve: Maia, you mentioned about grumbling that occurred in the beginning and I'm curious to hear whether that grumbling is still there and Alex what's your experience, was there grumbling on the mental health/behavioral health side too?

Maia: Very little when it comes to notes. I haven't had any recent complaints, and you know people tend to send their complaints my way. We definitely have had a lot of discussion about open lab results and pathology, radiology. That's where most of the discussion has gone as we continue to evolve our policy in opening access to patients to their data. As far as the grumblings, it's probably the same grumblings with labs, as probably the same grumblings they had with notes, which is you know, how is the patient going to interpret the information. Is there a risk of harm to the patient if they have access to a result that hasn't been discussed with them by their doctor or by somebody with some level of skill at interpreting the results.

Steve: Alex, how about your, any grumbling on your end?

Alex: I wouldn't say grumbling. The child teams have raised concerns at times when there's issues of custody. Issues of information in the record implicating parent's or others' behavior that might be accessible to someone else who maybe shouldn't have it. And I don't have an answer for that because some of that's complicated and legal, but amongst providers talking about the open description of why the person came in, their diagnoses, treatment and plan, people really have not grumbled.

Maia: If anything, it's been the other way because we have a couple of, if they're access I cut off – it's not really cut off, but for our adolescent population we have a proxy access where the parents have a very restricted view of what they can see in the electronic medical record. They can still request the record at any time, but the child can access the notes at any time they want, you know, but sometimes those 12 year olds just don't look at their electronic medical record. That is where there has been more grumbling. When somebody who is used to having a lot of access, then has a restriction of access because of the vulnerability of that population, that adolescent group.

Steve: Does that then change in terms of the level of access that a 14 year old has, as opposed to a 16 year old might have?

Maia: So the 12 to 18 year olds all get the same access, which is complete access. And then at 18 because the child or the adolescent is now legally able to confer proxy access to their parents, that's when we actually see another spike in parents requesting proxy for their now 19 or 18 year old child.

Steve: Huh, gotcha, a lot of the health systems struggle with that around the country, but it's not just in mental health notes really, it's in all notes in adolescent medicine. I think it's important that we think about how to develop clear supports and guidelines for how note sharing will work as children enter adolescence and then adulthood. Let me ask you, are there any notes types that you don't have open at this point?

Maia: I think they are pretty much all open at this point, except Alex can go into the very specific cases where they are not because they are actually mental health related.

Alex: Yeah, some of this is because there's law around some of the substance abuse record.

Maia: Yes.

Alex: It's a separate federal law related to substance use treatment records and so our records and our, I was talking about our dual partial program, or our intensive outpatient program. Those folks kind of contain their records in a different way because of often the legal … people may be there under court ordered treatment and so those records are not freely open because of the laws around them.

Maia: Yeah, exactly, and we've even gone to the step where when it's related to occupational health, employee mandated, they actually use a whole separate electronic medical record just because of the regulatory requirements and separating those records.

Steve: Do the providers there, particularly on the mental health side, are they able to sequester a note if they think, jeez this note is not going to be so helpful for a patient to see, or this note is really intended for communication to other providers, not to the patient.

Alex: When this has been brought up in meetings and they say, you know, "How can I hide notes?" We then start into the discussion of, help us understand what the reason is for hiding the notes, and then they start going into reasoning and then other providers will chime in and that just, that question has dissipated in these conversations, because I have not heard very many good reasons why these notes should be hidden. So, I haven't helped a provider or educated a provider in my two years here on how to make any note sensitive or know of any providers that are doing that. I know there's ways of doing it. It's just not something we do, which is nice.

Steve: We can all learn from each other and perhaps we'll lessen the fears or concerns by bringing these discussions out into the open, which can only benefit our patients. You guys mentioned stigma, the issue of stigma a minute ago and I'd like to shift over to that because it's so pervasive in mental health and it often times prevents people from coming in, getting the care they need. And I've got a comment here from Dr. Carol Novak who's a psychiatrist in Minneapolis who says, "Excluding mental

health patients as a group is categorically discriminatory and creates further stigma. I believe that making sweeping determinations to block records from patients suffering from behavioral health conditions amounts to treating them like second-class citizens." Do you agree with what Dr. Novak is saying and what would your staff say to that as well.

Alex: I'm trying to think of a recent experience where having a back and forth discussion was, like deciding whether or not to tell somebody a diagnosis and what they're, what the impact, are they going to be able to handle it emotionally if you tell them they have cancer. Maybe we should keep it from ma so she doesn't get too distraught or whatever. So, it just doesn't make any sense. And if we have any comfort that what we're doing is not alchemy, but actually a part of medicine and we're practicing medicine on the physician side or we are intervening in a complicated way with psychotherapy, we're disrespecting ourselves also by suggesting that these notes are different than other medical records that have often far more provocative content. I think it's unfortunate that it's behavioral health providers that are often contributing to this by suggesting this sort of secrecy and engaging patients sometimes in that, or god forbid they may be inadvertently treating them in different ways because of how they feel about things like the information they're communicating or writing down.

Steve: It's interesting that a lot of the resistance comes from the therapist community, so I think we contribute to the stigma by treating patients as is they can't handle the information, whereas if we treated that they can handle it, they're more likely to rise to that level than they are to decompensate as we worry about.

Alex: Knowing that a patient can read the note, it can be a trust builder, that somebody can tell me something and they can know that I can say, you know, she's really struggling with some complicated intrusive thoughts and that I can write what this is, and that she knows that to some degree she can tell me a secret.

Steve: I think you're exactly right, Alex. OpenNotes recently shared research suggesting that trust improved on both sides of the relationship, and that's such an essential part of therapy, particularly psychotherapy. I'm going to shift a little related to all of this. There's a comment from a therapist who talks about the ability of the open note to extend the therapy session, and I'm curious to hear what you think about OpenNotes as a tool within the therapy.

Lissa Kapust: I think the notes are very much a part of the therapy. I think there have been times when Stacey has come back and she's reflected on something from the note, a certain feeling or struggle she was having around a relationship, coming back and really using that again as kind of this springboard for conversation for the next meeting. It also, for Stacey allows her to do some of the work that we agreed upon between sessions.

Steve: Maia and Alex, your thoughts?

Maia: Patient engagement is a tough nut, and OpenNotes is one aspect of comprehensive patient engagement strategy, and for certain patients it is the notes that's going to be that key feature that helps them become more engaged in their care. For others it's going to be the lab results or imaging, but I think there's a lot of room and opportunity to continue to build a strategy and culture around patient engagement and really making sure that the patient is a full participant as well as a full responsible party

in that relationship and OpenNotes and really have access to as much of their data, all of their data is part of that.

Steve: I think you're right Maia that this is largely around patient engagement and I always think about the literature showing that when you're delivering bad news to a patient, that a patient generally only remembers about 30 percent of what you tell them, so they' don't' remember 70 percent. And then if you're delivering good news, the patient comes in for a well physical or a well visit of some kind, they remember about 70 percent of what you tell them. And so they're still missing 30 percent. And if they can then see what was in the note, they have a chance to reflect upon it, so that's what I often times think about both on the, certainly on the medical side, and also on the mental health side.

Alex: I will sit with the patient and write these things out and print it out for them, like here's what we're going to work on and here's what I'm hoping you will do before the next time, and even if it's simple behavioral instructions. And of course, that's still available to them so they so they can go and look at it on MyChart, but it's also a tool there that they can take and describe what our plan is.

Steve: Absolutely, having the opportunity to revisit it on paper or online can be a very positive reinforcement for patients.

So, I think some of our take aways here a little bit, write what you say and say what you write, and be up front about the diagnosis, and then think about developing strategies for patients who we might think might worry or be concerned or have some sort of effect. And then for those patients I would also add, you know, consider showing your note first to that same patient so they have a chance in the office to digest this kind of a note and see what it's about, particularly those that might be a little bit more obsessive. I mean our obsessive patients are going to be our obsessive patients and they're going to ruminate about certain things and you want to kind of head those off at the pass, but these are all again very predictable kinds of things that we can think about in terms of patient engagement and really increasing our patients' trust in us in the engagement and process of therapy itself.

Steve: It's been a pleasure speaking with you both. Thanks for sharing your experience with us, and I look forward to speaking with you again.

Maia: Thank you so much. Thank you for having us.

Alex: Yeah, thank you.

Steve: We've been talking to day with Dr. Maia Hightower and Dr. Alexander Thompson, from University of Iowa Health Care. They are early adopters and innovators in OpenNotes. You can find a transcript of this podcast and other information about OpenNotes at opennotes.org. And if you have a question for me, Steve O'Neill, I'm the mental health specialist at OpenNotes, you can send messages to me at myopennotes@bidmc.harvard.edu.

Thanks for listening.

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