

Oregon Medical Association

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Interviewed by Thomas H. Gallagher, M.D.

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Jim Dameron: The Patient Safety Commission believes that disclosure is of critical importance. It is the right thing to do; it's ethically based. We see physicians and hospitals having a stewardship role with patients to treat them in their wholeness, to treat them when things go well, to treat them when things don't go well. We believe that disclosure is a way to create an ongoing relationship, to tend to an ongoing relationship with a patient -- even a patient's family -- and we also think that disclosure says something about an organization's ability to learn from its own mistakes. If an organization can't disclose to itself, it can't disclose to a patient. If it can't disclose to itself, it can't learn from its errors. So, we think disclosure touches on a bunch of things, all critically important. It's ethical, it builds relationships, it says we are a learning institution. We can do better than we are currently doing.

TG: One of the things I think the Commission does a good job of is representing the patient and the patient's experiences and expectations. Have you gotten any sense from your work on the Commission what patients expect of the disclosure process?

JD: I think they expect some very basic, simple things. They expect the truth. They expect to be a part of whatever their medical experience is, for good or bad. So, they trust ... they want to trust their health care team. They're in a vulnerable position, they don't know as much about what is going on, often they're sitting there in their undies, they're vulnerable, so they need to have that sense of trust. That trust has to be earned. If things go wrong, patients want to -- they want some forthrightness. They want to know what happened. They want to know that it won't happen to somebody else. And they often want an apology, or at least a statement of empathy on the part of the hospital or the physician. *"This shouldn't have happened, here's what we're doing to fix it."* I think they want really some very basic human things.

TG: What are you hearing from patients about how well disclosure overall is going in Oregon?

JD: At least once a week I'll get a call from a patient who is not as happy as they might be about some medical experience. Often it has to do with an erosion of trust; the patient isn't quite sure what happened but they feel harmed somehow or injured somehow, so I think the expectations about disclosure continue to go up. It's become fundamental, it's an essential part now of providing health care. I believe that most patients would say, "Yes, of

course, I want my physician to tell me what happened, even if things didn't go according to plan ... even ESPECIALLY when things didn't go according to plan." Does it always work well from the patient's point of view? I would say not-- and that's part of the reason why the Commission is interested in this idea of written notification, which we'll get to in a moment. But, disclosure is an idea that's here to stay, I believe, and we as a medical, as a health care system, need to learn to get better at providing information about what happens, good and bad.

JD: Can we -- should we -- get better at disclosure? I think the answer is a strong yes. Patients I talk to are often aggrieved patients, so do not always represent a completely neutral sample. Often times I hear some frustration about what actually happened to *me*, the patient: *"I'm confused, I'm a bit dazed even by what happened. I thought I was going in for something simple. It didn't turn out to be simple. I'm seeking information, I'm not sure that my physician wants to give me the information."* When it goes well I probably don't hear about it as often, so that probably needs to be taken into account. But I think the evidence is clear that the expectations around disclosure on the part of patients is going up as part of a transparency movement, as part of full disclosure. We need to do this and we still have some things to learn.

TG: Oregon is one of two states, as you know, that requires written notification of patients following serious adverse events. Can you say a little bit about the rationale for written notification and how it fits into the disclosure process?

JD: Yes, written notification is an important subject and you're right, Oregon is one of two states: Pennsylvania and Oregon are the only two that have some requirement around this idea of written notification. The intent is to further link the physician and the hospital to a patient at a time when things don't go well. It's meant to reinforce a disclosure process. It's meant to "memorialize" the process -- which is a fancy word to say, *"Here's what happened and we're willing to put something in writing so you'll remember it, you can refer back to it"* It might have some contact information, too, but the intent is to say that disclosure is so important and so difficult that written notification is one way to aid in that process.

It's not been without controversy. It feels to some like a setup. It feels like some external agency saying, *"You must do this thing that feels fraught with risk."* Am I saying that I was a bad person and here it is on paper? That's not the intent. All the statute says is that a hospital must provide written notification after a serious adverse event and that it should be done in a timely way and it should be done in a way that's consistent with a hospital's overall disclosure policy. And I think that's the critical part. Written notification is frankly a terrible idea if it's divorced from a meaningful and well conceived disclosure policy. It's meant to be, again, an adjunct to that, an additional piece that codifies, makes sense of, provides some link back to the hospital in writing, for the patient. But it does not substitute for a well conceived, well considered oral disclosure policy.

TG: Some physicians might wonder, if I do oral disclosure well, why should we even bother with written notification? Isn't effective oral disclosure sufficient?

JD: If the question is, 'if we the physicians can do an effective oral disclosure, why would we need written notification with all its incumbent risk?' Well, I guess, one challenge back would be, how do we know it's done well? Whose word do we take for it? I think that a dazed patient, a confused family, a situation in flux, it's difficult to know what's coming through, what gets through the ether from you the physician to me the patient – it's hard to know for sure. There might be a lot of head nodding, there might be a lot of tentative agreement as a nervous gesture, but it's difficult to know. So, written notification simply is another way to reinforce the essential message. And again, the Commission doesn't dictate what should be in that message. It could be as simple as, "We're sorry that this event occurred, if you have questions here is a phone number to call." Or, it could be as elaborate as, "We apologize for this, and we're going to investigate this and here's the number of our CEO if you have questions, and we promise to call next week to tell you what we've learned..." I can imagine a skinny version that simply says, "Here's some contact information or we acknowledge that something's occurred," or an extended version that actually starts to list actually a game plan on how the hospital will cope with, deal with, share information about the serious adverse event. So, those things, I believe, reinforce the disclosure policy, don't undermine it; even if you believe you are doing a good disclosure, this makes it more concrete. It gives the patient or the patient's representatives something to literally hold onto, to leave the encounter with, to refer back to. And we believe those things will simply reinforce again that good disclosure policy.

TG: It sounds like written notification will not only improve communication with the patient, but also to provide some dimension of accountability around disclosure? Is that right?

JD: Well, I think the primary thing is to make disclosure work better, and to try to take into account the patient's point of view. I, as the patient, might not be taking it all in, but there is something to your idea of accountability. It says, now we know that disclosure took place, we now know the patient was there, that the patient got some information. It's a way to say to the world, to the patient: *"Yes, we believe in this strongly enough to actually put something into writing."*

TG: So, where do you see physicians fitting into to the written notification process? It sounds like this is the hospital's responsibility.

JD: If the question is how do the hospital and the physician work together, how does the physician fit in to this idea of written notification, it's an important question. The statute that puts this into play mentions the hospital, not the physician, so that's a potential tension, and we need to be careful of that. In the best of possible worlds, we believe that, again, the written notification should fit inside this bigger disclosure policy. A good disclosure policy suggests that there is agreement between the physician and the hospital

on how to handle an adverse situation. If there is an agreement, a policy, a compact -- then the written notification would tuck inside that. When that is NOT the case -- and my travels around the state suggest that it often isn't the case -- then there are some tensions around who's in charge here, who's responsible, who's accountable for this, and then written notification can feel a threat. Who signs the letter? That's not such a simple question. That's an intimidating question; who's responsible for the contents of the letter? Again, best world, we believe the CEO, board member, or some high level administrator and the physician should both sign the letter, should both agree to its contents, should stand shoulder to shoulder; there should be a "we" inside that letter represented by the signatures on the bottom of the page. If that doesn't happen ... and there's some reasons why I think it might not happen ... then it's more difficult and that needs to be worked out.

TG: What about the issue of a serious adverse event that happens outside the hospital ... in a physician's office or some other out-patient free-standing environment? Where does written notification fit into those sorts of events?

JD: The obligation to provide written notification applies only to care given inside of hospitals, ambulatory surgery centers, nursing homes, so those kinds of organizations. So, it's limited by facility type and by the kind of event. Only THE MOST serious adverse events would require that -- something that led to a death or something that led to serious physical injury would require written notification. If it occurred in a doctor's office, this obligation would not apply.

TG: So what aspects of written notification do you think are going well and which aspects do you think are in need of improvement?

JD: What is doing well with regard to notification and what is not going so well? It's been a struggle. Again, as you said, only two states are doing it so there isn't any great model in the world for how to do this. Disclosure itself -- oral disclosure -- is still a new movement so we still have much to learn. There are, however, some hospitals in the state, a minority of them, who have embraced written notification and believe that it works. They've integrated it into their disclosure policy, they like the way it focuses the hospital's attention on what they would consider patient "centeredness." It's as if, *"OK, if we're going to sign this letter and if we're going to tell the truth in this letter we, the hospital, have to be very thoughtful about what we're willing to say."* It forces that reckoning. That's useful and hospitals have embraced that. It forces an alignment between physician and hospital ... sometimes painful, but useful. So, in the minority of hospitals that have figured this out, they like that. Ahhh, the challenges? It still feels to some like a threatening risk without any clear reward. It feels like a bureaucratic imposition at its worst. It feels as if there's a lack of trust on somebody's part -- the Commission's part, or somebody's part, about a physician's ability to do good oral disclosure, and so those are things that we've had to overcome. I guess the most difficult personal one for me is that it's in statute, so it's easy for someone to say, oh, it's just the legislature, yet another thing that some external body is telling physicians to do. As administrator of the Patient Safety Commission, it's my job to enforce

that statute. So, I'm between a rock and a hard place, as it were. But our attitude about this is that we have not rigorously enforced it because we think it's too new, we think it's too hard, it's still in development, so we've taken a go-slow approach. Which isn't to say we're trying to give people a free pass. We're going to make this work, but we're doing so in a thoughtful way. We're doing so with as much input as we can muster, with as much information about the difficulties as we can muster. But, back to basic principles, the idea is a good one. It's just tucked neatly, in our opinion, inside the disclosure movement. It's the ethical thing to do, it links you the hospital, you the physician, back to your patient in a meaningful, demonstrable way, it says we care enough to dig deep into our own errors and learn from them because we're saying we're going to be accountable for that. If you say in a letter, "*We will investigate and tell you what we found,*" you're forcing yourself to be a learning organization. Those are good things in our opinion.

TG: So what do you see as the future of written notification in Oregon and how is the Commission planning to help move toward that better future?

JD: Well, again, I think, I believe, I hope written notification will have the same future as disclosure in general -- and disclosure, as we've said already, is here to stay. There is no impetus to go back the other direction. We will learn ... we need to learn ever more forthright and direct and clear and honest ways to talk about and discuss medical errors and adverse events. Written notification? I think that we'll figure it out. I think at the least it will be a way to make concrete a difficult conversation, to demonstrate at least some rudiments of what a commitment to a patient means: *Here is the person to call, here's what we're going to do, here's what we'll share.* Those things, I believe, are useful and straightforward, so I believe those pieces will catch on.

TG: Just in summary, what are the most important things you would want Oregon physicians to understand about the written notification process?

JD: I think I would like to clear away any confusion, any clutter, and say the essential idea is that it's meant to reinforce good disclosure, period. And because of that it can never be a stand-alone document. I would hate for our physicians or hospitals to feel that they have taken on the obligation that, absent any conversation with the patient, absent any relationship with the patient, that they would still somehow need to send this letter to a patient out of the blue. That would be a terrible idea. That would be a destructive idea. So, a central piece to communicate is that written notification is just a small part of a larger disclosure movement ... a disclosure process, and the challenge is to find a way to mesh the bigger disclosure with the more narrow written notification. There are many ways to do it: is it better to give a written notification at the beginning or the end of a discussion, or the beginning or the end of an investigation; what is the best content, because there are different ways to do it? But the central idea again is simply to remind physicians and hospitals that the challenge is to do better disclosure; written notification is simply a small piece of that.

TG: Are there other things that you'd like to share about the Commission's perspective on either disclosure overall or written notification in particular with Oregon physicians? We've covered a lot of great ground. Is there anything else...?

JD: The mission of the Patient Safety Commission is to help reduce the risk of adverse events and to encourage a culture of safety, and one of the ways we do that is through voluntary reporting; we're the only state in the country that actually has a voluntary reporting program. We think we've done a pretty good job of reaching out to hospitals. Of all the hospitals in the state, only two have not decided to participate. So, voluntary decision, almost all have agreed to participate. I believe that we are doing a good job of communicating what kind of information we are seeking, with quality managers of hospital and with the risk managers, even with the administrative team of hospitals. I think we're probably doing a less effective job of communicating our intent and our needs with physicians, so if I had an appeal directly to physicians it would be, how can the Commission get physicians in Oregon who work in hospitals more involved in reporting of adverse events to the Commission? It's voluntary, information is confidential, it would never be shared with anyone except in aggregate, our intent is to create a learning tool so that, if an error occurs here it won't occur there. So, if you have a good idea we can help share it across the state.

This fits into the disclosure piece because it triggers a disclosure or written notification when an event is reported, but it also speaks in its totality to what a culture of safety is. And part of that is that you, the physician, are part of a team, you are integrated into the hospital's quality programs, you're willing to share information and we all believe we can learn in some better, deeper way if we share that information and we dig deep and investigate that information. So: help report events, ask your hospital, "*Did you report this to the Commission?*" Take part in root cause analysis teams -- I think physicians can do more of that -- and as you do differential diagnosis for clinical, do differential diagnosis for systems issues ... why did this error occur? That's a systems issue. Physicians are good about thinking about what are the differential possibilities, what are the probabilities that it's this kind of error or that kind of error. I think we need that sort of thinking more than we currently have.

TG: This has been great.

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