

Nursing Competencies and Genetics Training
Elizabeth Pestka, M.S.

DR. McGRATH: Beth, I'm sorry you have to follow that. That is quite a challenge.

Beth Pestka is at the International Society of Nurses and Genetics.

That clip is probably on You Tube already. It was probably there within moments.

DR. TUCKSON: I'm told that you can Google it, actually.

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MS. PESTKA: This is really a wonderful opportunity for me. I am brand new to this type of an experience, so it was very exciting. My family thought I was really getting important in the world to come to Washington, D.C., and speak to a group such as this.

My name is Elizabeth Pestka. I usually go by "Beth." I was invited to speak to you today on behalf of nursing. There are 2.9 million nurses in this country, so it is the largest group of healthcare providers. I am from Mayo Clinic in Rochester, Minnesota, and we were identified as having an exemplary model of genomics education for our nurses.

Sometimes people will say, "Are all your nurses educated?" It is like, no, I don't promise that. "Are all your nurses competent in genetics and genomics?" No, I won't promise that, either. But we are making some really good headway. So I'm going to share with you an overview of nursing and then, more specifically, what we are doing in relationship to our program.

Prior to 2004, there were many excellent initiatives in the profession of nursing. If you had the opportunity to look at any of the articles that are in the package, you can reference some of those initiatives. But they weren't real condensed and real planned type of activities. There were some scattered things that were making some good inroads.

What happened in 2005 is that two individuals from the International Society of Nurses and Genetics and also who work for the government here in Washington, headed up a group. Their goal was to get more of a concentrated and more of a cohesive plan for how we could integrate genetics and genomics into nursing. They started work in 2004 contacting nursing organizations.

With such a large body of nurses -- there are about 80 recognized nursing organizations in this country -- they actually were able to garner support from 48 of those organizations. That is pretty amazing. That is a very, very high percentage, especially when you think nursing is mostly women and women don't always tend to agree and see eye-to-eye on everything. I think that is really an amazing accomplishment.

In 2005 then, there was a meeting to endorse the essential nursing competencies. The two individuals who deserve an enormous amount of credit for working on this are Dr. Jean Jenkins and Ms. Cathy Calzone. They have done phenomenal work on organizing and bringing consensus to this whole program.

In 2005, they gathered individuals from these organizations who were interested in endorsing genetics and genomics competencies, and did come to consensus. Those competencies are listed in your packets.

What happened then is the support of these organizations, and in 2006, last fall, there was another meeting to identify an integration plan. So this is for implementing these competencies into education as well as into practice. Again, just an extremely excellent oversight and overview of how we are going to be doing this.

In the implementation plan, there are three focus areas. First of all, the nursing academic focus. If we don't prepare nurses of the future, we really won't have anything to work with. Secondly, practicing nurses, and thirdly, regulatory and quality control focus. So there are any number of items identified under each of these categories.

Dr. Ann Cashion is going to speak a little bit more to nursing academic focus a little while later, and so what I'm going to primarily talk about is practicing nurses, because I am a nurse in practice and I work with many thousands of nurses in practice at Mayo Clinic.

What is the plan or what is the theory that this whole implementation plan is based on. It is Everett Rogers' Diffusion of Innovation Theory. I had the opportunity to speak at length with Dr. Jean Jenkins in September. She came to Mayo Clinic to speak at one of our conferences. She said normally this process takes about 17 years, but she said she is far enough along in her career she doesn't want it to take 17 years. So the plan is set to take place in five years. That is the goal for this plan.

In the Diffusion of Innovation Theory, there is the knowledge stage. So we need to educate nurses on what is genomics. I love it; at Mayo we sometimes have some of our nurses go out to other conferences and they come back and say, "Can you believe it? Nurses at these other places don't even know what genomics is." It is like, think, a few years ago did you know what genomics was?

We do use the term "genomics" quite liberally because we want it to be inclusive. We don't want it to be those pure genetic disorders, so we use the term "genomics" quite liberally.

Then there is the persuasion stage. Why is it important relevant to me. We have certainly learned that it has to be very specific. What is convincing to a nurse in orthopedics isn't convincing to a nurse in hematology, or isn't convincing to a nurse in psychiatry. So it has to be very specific. We have to have information and examples for each subcategory.

Then the decision-making stage. Is genomics worth the effort. Is it really something I want to put my effort into. People are busy. As has already been mentioned, time is of the essence and there are so many competing priorities. Is this worth the effort.

Then the implementation stage. How do I include genomics in my practice. Primarily, what does it look like. Again, this has been alluded to, and I would like to speak to that a little bit more.

Then, finally, the confirmation stage. Am I competent in utilizing genomics in my practice. Again, what does that look like.

At Mayo Clinic, in 2001 our leadership said genomics is the future of health care, no doubt about it. Absolutely no doubt. Our president and CEO, Dr. Denis Cortese, said the future of health care lies in translating genomics advances into practice. Patients will go to the providers that are best informed and best equipped to provide genomic services.

So this has been a prevailing theme, and we certainly have been moving in this direction, to the point that we are establishing a center for individualized medicine based on genomics information. We aren't there yet, but we are moving in that direction.

One of the things that was really pivotal for our program at Mayo Clinic was receiving the Magnet Prize. This has been described as the Nobel Prize in nursing. We received it for our nursing genomics program. This was very, very exciting. But again, it brought tremendous national and international attention to genetics and genomics education. People who hadn't considered it before were thinking, "My gracious. This got the Magnet Prize. This must be important stuff."

Actually, even on an international basis. Recently, I was invited to Singapore. They really are seeking Magnet status, and they said, my gosh, this is Mayo Clinic and they got the Magnet Prize for this program. We better consider doing this. So they were really motivated. They were like, if we invite you back next year for two weeks could you get all of our nurses competent in genetics and genomics? I'm like, I don't think I can do that, but I'll come back anyway. It was a great visit.

But it is very important because this has generated a lot of interest and a lot of focus on genetics and genomics. It was recognized for a very grass-roots effort.

What I would like to say is our organization says genomics is important, the profession says genomics is important, and most importantly, our patients say genomics is important. I have a very brief video clip. This is one of our patients. It is an unscripted, unprompted recording. He did consent to this. But I just want to point out how really important [this is.] Patients come with high hopes for genetics and genomics, and we need to realize those hopes. We need to realize what they are looking for.

This one ties in especially well for this group because he is speaking to pharmacogenomics, which we are actively using.

[Video presentation.]

MS. PESTKA: That is a pretty powerful story. James certainly has high hopes for genetics and genomics. We certainly aren't there yet, but he did come specifically for the pharmacogenomic testing because he has been on so many different medications. He has suffered and struggled so much that he is hoping that this will be something that will be able to help him out as well as his family members.

We have done a series of these video clips related to other diagnoses, and these really sell the education. It grabs that affective component. It is not just the intellectual, it is the affective. These are real patients, these are real issues, and they are looking to us for answers. They are looking to us for care. So it is just a really powerful series.

Just a little overview of what we have done to enable us to receive the Magnet Prize. We have a very diverse program. We started it back in 2001, when the rest of the Mayo Clinic said, okay, we have to educate everybody. Again, it has been incremental and it has been step-wise, but we are moving forward.

We did presentations to the leadership groups, and articles. We started a nursing staff development curriculum, which is a four-hour class that is available to nurses. We have had

posters at every single nurses' poster fair for the last years, starting in 2002, just to keep it there and keep it visible. A lot of specialty education methodologies, so we have had a lot of things going on.

We do have a wonderful intranet specific to nursing at Mayo Clinic, and it is being utilized more and more all the time. I haven't been measuring the hits but probably should be because I know the use is increasing. I'm getting more and more correspondence.

In our nursing conferences, we include genetics and genomics in almost every single one. We sponsor about a dozen conferences every year, and is becoming more and more prevalent in our nursing specialty curricula. So when nurses are beyond their general orientation, if they are going into hematology, oncology, of course they get some education on oncogenesis. If they are in psychiatry, they get the pharmacogenomics stuff. If they are in other specialties, there is some genetics and genomics integrated into all of the specialty curricula.

The centerpiece of our whole program, the most exciting part, is our nursing genomics interest group. So we invited all nurses. We have over 6,000 nurses at Mayo Clinic Rochester. Anybody with an interest could join this group. We started out with about 30 people. Now we are up to over 100 individuals, and they are doing marvelous things. Very grass roots, but they are doing marvelous things in teaching their peers.

We started with two things, and we have added a third. You have to learn yourself, you have to teach your peers, and then in this last year we added you have to start role-modeling the competencies. So we keep it pretty simple, we keep it pretty real, and they don't have to be up and doing big presentations. They can do a bulletin board on their unit. They can do a binder of articles. They can do anything, but they have to do something. That is the expectation and the accountability piece.

Then, there was a list of competencies, but still that was too vague, too general for our nurses. So we said we will help you out here. We will show you what it looks like in the nursing process. So we took those competencies and we put them into the nursing process. We said, part of your assessment should be the family history, pedigree, environmental factors, physical findings, and patients' knowledge and questions. Use that in planning.

Then the interventions would be doing patient education, discussing family risks, discussing preventative measures, testing, treatment, and pharmacogenomics. Nurses are great patient advocates, so discuss some of those ethical, legal, social, cultural issues as well as support services, and then the genetics referral if indicated. Then evaluate the services provided.

So we put it into a format that nurses were used to looking at and they could sooner get their arms around it and say, okay, this is what it looks like. We said we will make it even easier for you. You don't have to do all of these right away. If you do two of the assessment items and two of the intervention items right away, we are happy. That is a good start. So that is what we are working on with our nurses.

Actually, this model is accepted for publication in the American Journal of Nursing. It should be coming out soon.

What are some of the barriers and recommendations. Again, these have been cited already. I'm sure they will be cited by our other speakers. Time for education. Time is valuable, time is

limited, time is a challenge. We are saying integrate it into the existing programs. Don't create new programs. There isn't time or resources.

Time to implement and practice. Again, huge challenge. Everybody is busy and racing. There has been more expected with less. But just keep it very simple, relevant, and realistic. Don't expect that everybody is going to do everything because that is not realistic.

Time to evaluate competency. Again, very simple, relevant, and realistic.

Lack of education resources. One of the things that happens is we get invited quite frequently to consult or present at other organizations, and they will say, "You have these marvelous resources," especially our series of recordings. "Can we have those? Can we use those?" The unfortunate part is they were done with private funds. So it is like, I want to share them really badly, but I really have not been at liberty to do that. Occasionally I do. I'm not supposed to. I really want to be able to share the things that we have developed.

What we are developing now is a series of nurses demonstrating exactly how they are using the competencies. It is so incredibly valuable, so I really want to be able to share those. I was invited to speak at a national staff development conference in the summer, and it is like, oh, I would love to be able to share all of those things that we are developing, but I don't have permission to do that.

What we really need is federal funds or non-private funds to develop more relevant resources for all specialty practices. Again, those series of segments that are very relevant to different specialties.

Then we definitely need a centralized location for resources for all nurses to keep that up to date and to identify those gaps and develop things that need to fit into those gaps.

Again, it needs to be very specific. General information just doesn't cut it. It has to be very specific to nurses and very specific to specialties for nurses to really buy it and really embrace it and engage in it.

We definitely believe that genetics and genomics is the future, not only for our organization but for all the different professions in health care. It has just been an exciting opportunity to be working with genetics and genomics. I have had other assignments concurrently, but I always say genetics and genomics is my passion. That is where I really am excited and really see the future going. I really enjoy moving that initiative forward.