



Division of Diabetes Treatment and Prevention

Advancements in Diabetes

Leveraging Cultural Capital in Diabetes Prevention for Youth: The Medical Wellness Model

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Jennie Joe:

I don't know what that means, but I'm trying very hard to be retired. But I'm doing work with a number of Native communities and continue to be very interested in many of the chronic diseases and particularly those that are a problem and a growing problem for many of our Tribal and Native communities, including diabetes.

So these are the kinds of things I think that are important that you can't just retire from. So I'm glad to participate and I have actually convinced Francine to join me because she has taken over this particular intervention when I got to retire and has blossomed the program even more. So a good portion of our presentation is going to be devoted to the kinds of things that are happening now currently with this model.

Francine Gachupin:

Okay, thank you Jennie and hello everybody. My name is Francine Gachupin and as was mentioned I work at the University of Arizona. And I'm very interested in doing behavioral interventions for chronic diseases in American Indian populations. And for this particular presentation we will be talking about youth and my background is really in epidemiology. I have a Master's in Public Health from the University of Washington in Seattle and have been trying to develop projects here with Southwest Tribes to again address the health disparity that we see. And so we're hoping that this will be helpful to everybody. And even though this is a webinar, we're hoping that if you have any questions that you chime in and that we can make this as interactive as possible given the format.

Jennie Joe:

Okay, we're having a little technical difficulty here trying to move the slide down. I think one of the things that is evident and most of you know this very well, so it's probably just a good overview, but I just happened to pick up the Time Magazine this week and happened to look at a big page that focus on type 2 diabetes and the epidemic situation that it is creating and how expensive it is. And I think we are very well aware of that.

The estimates are that by 2050, one in every third American will probably have type 2 diabetes or diabetes. And presently it cost \$245 billion dollars, much of it going to complications associated with diabetes. So it's a very expensive disease and it certainly can cripple the health care delivery system. And particularly in our situation when our healthcare delivery system is not well funded in any way, so I think that's important to keep in mind.



The kinds of prediction that's happening here are things that you're familiar with and the data seems to indicate that American Indian/Alaskan Native youth, between the ages of 10 and 19, diagnosed with type 2 diabetes is much higher than it is for non-Hispanic whites as you can see in the slide. And the increase has really continued to climb since the 1990s. It rose from 3.24 per thousand to 6.81 per thousand.

The risk factors again is an area that everybody is well familiar with. I think we have seen in the ADA risk factor category, they always mention that if you are a Native-American, you're at risk. What we do know is that if you have a higher percentage of Native ancestry, if you're a full-blood Native, your chances and your risk factors are much more urgent than someone who may just have one-quarter Native blood. So there's a strong family history and particularly for young children if they have type 2 diabetes or diabetes in their first degree relative, it's an indicator of a risk. Gestational birth is another one. Low birth weight is another risk factor. My experience, however, and I think it's for many of you, babies born in gestational birth situation tend to be of higher weight as well. So it doesn't always come out that way that most babies at risk of developing diabetes or have low birth weight.

Childhood obesity of course is something that everybody is really concerned with and certainly an important way of looking at prevention. And the other indicator is of course clinical, the ones that have to do with impaired glucose tolerance. And one of the symptoms or signs that we have to look for particularly in young people is the acanthosis, which is really kind of a patchy dark patch of skin that happen either in the neck area or under the arm. This is among many of the risk factors that you're well aware of. So I'm just doing a quick overview.

I think the other has to do with the impact. And the impacts are the complications that come aboard with the particular health problem that we're addressing. Some of the areas that I think we have kind of anticipate or know it's there, but we give a very little voice to has to do with the social/cultural difficulties and stress that they've associated with this. And Ann Bullock's classical presentation always talks about maternal stressors being a factor that really increases a lot of health difficulties for an unborn baby and certainly childhood as well. Poor quality of life, I think if you're a young person who has been diagnosed with type 2 diabetes and you already had it with complication, your quality of life is severely compromised. And that's something that we really have not fully addressed, I think, in many ways. We just know the medical cause, we don't know about the human cause.

And one of the other thing is poor self-management that does come at the cost of leading to other complications and hypertension of course and then of course all of the visual and other types of complications that often lead to some sort of application or end-stage renal disease and certainly premature mortality.

The treatments again are something that you're all pretty much familiar with. So I know that with children, metformin is still the choice of medication for many of the kids. It was really interesting when we first started this particular focus on young people. There were really no treatments available because nobody expected kids to develop type 2 diabetes. It was in fact called adult onset diabetes. Now, many of the children that we deal with in one way or another that is usually the medication that they are on. In many cases it gets complicated for them because metformin also increases their appetite. So sometimes that becomes kind of useful but not always useful situation.

Increasing number of children are being started early on insulin. Very few can afford insulin pump which is probably something that's more popular in other parts of society than in ours. Many of the children also have a lot of comorbidity as maybe in some cases hypertension, so they have medications that require those kinds of other intervention as well.

Surgical intervention is something people talk about. I think most of it is really expensive. I think that the kinds of costs are coming down but I don't know well enough how many Native children have had that option available to them.

And of course we are having a lot of focus on lifestyle changes. We're doing a lot more in way of health assessments and we're also doing a lot of community-based programs to improve nutrition and eating habits even in the school system. The other of course, is a big focus on physical activity and really making sure that there is ample time for children to be active. And so those are the kinds of interventions that we're seeing out there and I think that it needs to all happen in every level, not just only in the medical arena but in the community as well.

And the other very important part of this is developing a real comprehensive but meaningful type of diabetes education for young people. We seem to have borrowed much of the idea from the adults with little attention to making them a little bit more relevant for young people. So I think that's a challenge for us and we need to take that head on. I think the books that have been developed and are being used in the classroom are nice, but you really need a personal one-on-one interaction particularly taking a look at the new data that says things like family spirit, where you have home visitation, makes a big difference in the way babies are treated and the babies are raised, and the learning that happens and the kind of choices that happen - they are much more positive and lead to more ideas of realistic prevention ideas. I think those are the kinds of things that we're seeing developed. We are sort of at the starting stage of doing something a lot more meaningful and being a lot more creative.

The whole idea of Leveraging Cultural Capital in Diabetes Prevention for Youth is something that I think we need to come back to and that's really to talk about what are the kinds of capital or strengths that are available in the world that we live in now. And in many cases some of the traditional ways have a lot to offer from this point. So I think that's the reason why I think the model that we're going to be talking about really takes into account those things that resonate or have some meaning for young people as well as people who are engaged in this particular model, everything from the idea of shared norms, belief, expectation, and community customs.

Youth in particular have a stake in more than one culture, there's the youth culture, there's of course their community culture and then there's the more kind of international kind of culture, the kind of music and technology that is sort of part of their daily life. And from that they really have new things that they add to their cultural lifestyle and we should really be careful to sort of say these things come together and those things that are useful are very important. For instance if you have a child who has no talent and maybe no knowledge of speaking their language, but they are very fluent in English, then the kind of educational program you develop for them is going to be different than the young child who is bilingual and maybe has a better understanding if the particular health education speaks through both of those systems to reinforce the message and I think that's important.

I know in a way of retrospect, in 1991, we did our first wellness camp. Actually we did a conference on diabetes in 90s when I came here and we were talking to a number of healthcare providers who were telling us that they were seeing children that had all the symptoms and clinical evidence of type 2 diabetes, but they didn't know what to do with it. They didn't know how to help them other than to talk to them about physical activity and diet which of course was not working out very well of course. We took the initiative to the start putting together with a number of communities, particularly healthcare providers, in developing models, looking first of all at the ADA camp, residential camp model. And we made changes to really focus on type 2 diabetes.

And so we had our first camp in 1991, and as you can see here in the picture, it's a collection of community workers, community healthcare providers, young people and lot of adolescents. I would say probably 90% of the people who have come to the first camp were at high risk because it was sort of the first calling of such an activity and it was a one-week camp that we held at a facility that was part of the ADA program here in the state of Arizona.

Having the first camp led us to develop some new ideas about what works and not works. Some of the lessons we learned is that we really need to make the camp environment a friendly one. And in this

particular camp that we have now, all but the kitchen staff are from Tribal communities. That reinforces the notion of connectedness with the community, familiarity with people we trust and certainly relationships that are also part of that because we have a lot of extended kinship assistance that's always there. The medical team is an important part of this and it's kind of a new relationship for young people to start really having a kind of one-on-one and more friendly dialogue with medical teams, that they really won't get a chance to do when they go to a clinic or in some sort of medical visit. And the other thing that we really start taking a look at from our first experience is that many of the children that were being diagnosed were between the ages of 10 and 15, so we decided to target that age group. And we started taking a look at risk factors. And we know the things like BMI and strong family history of diabetes and variety of other things like impaired glucose results that might be happening. Most of the children who come to camp have a thorough physical exam so we know the medical situation when they come here. There is a medical and a family application that is done for each child that are recommended to come to camp.

We put some amount of activity into the curriculum. We really make sure that what we had in the way of dietary offering and physical activities or things that these kids can do and do it well without introducing anything in the way of high tech things that may not be available in their own community. Diabetes education was something that we really had to get a good handle on. We needed to find out how much they already know or don't know. And so, that was one of the things that we wanted to do is to get a handle about where were the weaknesses that we can address while they're at camp.

We made much of the activity also resonate with things that are important as the Indian child grows up. Storytelling, traditional games and variety of artists that come to serve as role models, but give the camp a chance to sort of experiment with different kinds of things and so they can get their creative juices flowing. And we have made a big effort to work in collaboration with medical providers and we also make sure that a child who comes to camp who is on any medication whether be insulin or an oral agent, that they really know what it is, what are the side effects and what are the kinds of questions they should be asking the provider if they feel like something different is happening in their body. And the other thing is that we really make sure that we do referrals back to the providers so the child is not lost after coming to camp.

The next series of the presentation are going to be covered by Francine who I said right now and is really much more involved in the day-to-day or yearly activity of the camp.

Francine Gachupin:

So one of the things that I think many people on the call are very familiar with is doing measures. How do you know whether you're making an impact and what are the effects of the program that you're introducing individuals to and what are your outcomes? And I think more and more as we apply for funding you need to provide that justification. And so that's one of the things that we've been doing at camp is trying to measure our effectiveness. And trying to again provide that feedback to our funders but also providing that information to our community partners so that they can leverage it for their own activities locally as well as for their own funding needs or for their reporting because we all have to report to higher ups and so it is multifaceted.

And so at camp, a typical week involves assessments where we collect baseline data at the beginning of camp, at the end of camp, and really now working towards extending that once the kids leave camp and when they return to their home community. And while the kids are there as Jennie just mentioned, we do a lot of nutrition education, a lot of diabetes education and then in the site here you can see some of the photos from an actual camp. These photos were taken from the camp in 2014. And then we do a lot of interactive group sessions. Here is a chance for kids to become familiar or be introduced to kids from other Tribal communities.

And so we try to do a lot of interactive group sessions so that they all get to meet people and learn about each other, learn a little bit more about where individuals are coming from. And then of course, we do a lot of physical activities throughout the day. We have about five structured 50-minute sessions. And then we have open time as demonstrated in the Tribal traditions little side, in that we bring again not only core people who help with the administration of the camp but we also invite guests who come to the camp with the idea that they're promoting what Dr. Joe just said about cultural capital and here in the slide is we have traditional games. And so we try to instill in different parts of our program, elements of introducing kids to culture and not assuming that they're coming with a background in that area. And so we try to introduce them to these different things.

Every morning, our day starts out with one of the participating Tribes talking about their community history, talking about their language, talking about their different cultural activities, belief systems, and so we try to integrate that as fully as we can within the curriculum. And as has been mentioned, this activity would not be possible without the partnership that we have with communities and so many of the individuals that come to the camp are from the southwest Tribes both in Arizona and New Mexico, and typically involve individuals who are placed in Tribal Health Departments with the Indian Health Service, with different diabetes programs especially the SDPI programs, the different wellness programs. If there are fitness centers for example, we have individuals who are instructors of the local wellness initiatives come and teach and lead the classes that we offer.

We have ongoing planning. Of course, this takes a lot of effort to structure and to organize these activities. And so we have access planning committees and these usually meet every other month especially leading up to the camp itself. We have volunteers that come from the respective communities that stay there for the entire week and serve as counselors for the kids. We break up the kids into cabins, and so a lot of times these Tribal volunteers are in charge of the kids within the cabin. We share the cost for the camp. We write a lot of grant applications to small funding entities, but then Tribes also pay for the kids to come to the camp a lot of times because this can be a financial hardship for private families, and so we try to share the cost for this experience.

And then the different assessments that I'll go into more detail in the next slide is we make sure that all the things that we're doing that we provide results back to the community so that again they can leverage these for different things that they're being responsible for locally. We write an annual report so we write up all the results of the different activities that kids are involved with, and on the right-hand side is a copy of the report from last summer. And then we do follow-up within the different communities and each of the individual communities do different types of follow-up. At one community, we know that they actually have winter camp where kids who go to the summer camp are called back together and are kind of regrouped. We have different communities that are actually following up the kids one on one and looking to see what kinds of -- the education has been retained. And so we're trying to develop that in a more structured approach going forward.

The next slide shows a little bit about our documentation and our training. And so in the assessment, we actually have a lot of the forms. We have the protocols developed. We actually do training with all the individuals that are going to be responsible for the different stations that we set up. And any of the tools that we make reference to in this presentation, we're more than happy to share. If you just send us request, we'll be more than happy to share those with you. The different measures that we're collecting include age, sex, height, weight, age, glucose measures, cholesterol measures, we're looking at physical fitness and using objective measures for those, doing nutrition assessments and then looking at risk factors that the kids actually have. Because as you know, this camp is for individuals who are high risk for type 2 diabetes or have been diagnosed with diabetes. And so we're trying to figure out the prevalence of these different variables within our population.

And so the next couple of slides just give a brief overview of the data that we collected from summer 2014 where we had 35 kids. And this is very typical. Usually, we have about 33 to 40 kids come to camp and we found that to be a pretty good number in terms of the counselor to camper ratio. And it

allows us to then really again, as Dr. Joe mentioned, be able to provide that one to one interaction with youth, and to really again follow up on some of the education that we're promoting in these different sessions that we offer.

So we collect blood pressure and these are point in time measures. We collect heart rate and then waist circumference which has been indicated as a very strong predictor of risk factors for obesity and then we collect A1C and fasting cholesterol and glucose. And through the different funding that we've applied for, we've been able to build our inventory of the different equipment and supplies that we're using to collect this information. And we use a software called REDCap to keep all the data stored. And this is a web-based database, so I'm hoping that at some point that our partnership with the Tribes will allow them to actually be able to also go in and be able to recall their own youth data from their respective Tribal communities.

And so I won't go into detail on the results but I do want to point out on the A1C for example is that when we look at the range, the range was from 4.9 to 10.8. Already, we see that there are kids that have some pretty high values, and then likewise for fasting cholesterol and the fasting glucose. And so again, these are indicators that then our medical staff can use to talk with individual youth about some of their risks and then to really again promote some of the education on a one to one basis based on individual results.

We also, again, I said that we do measures on physical activity, and so we do something called the PACER 20-meter, and this is a measure of cardiovascular fitness. And so we have kids who run between two points that are measured. And the time that they're allowed to go from point A to point B is measured, and we measure how many laps that they can run and the higher the number of laps that they can run, the better their fitness. And so we had kids who could only run two laps and so we want that number to be high. And then we also were able to purchase Tanita Body Composition scales, and so we're able to provide feedback back to the kids about how much percent body fat they have, how much fat would weigh, how much the lean body mass is, and of course body mass index as an indicator of again obesity as a risk factor for diabetes.

Then we've also been incorporating technology more and more in our program as an objective way to measure physical activity. And this is the slide on results from our polar loops which are very comparable to Fitbits. If you're following up on some of the things that we hear in terms of physical activity using technology, and this is just a snapshot of kids at the second day of camp. We actually gave all these kids polar loops on their arrival. So this is the second day that they're wearing them.

And the active time that was tracked by the -- this is aggregate data. The amount of active time that was tracked for the youth was nine hours of active time. And even for the youth who was the least active, they were still active for four hours and 51 minutes. The number of steps taken was 27,781, and if you look at the range, the highest was 41,000 steps. The device gives back information on the kilo calories burned and then amount of sleep. We know that sleep is a really important variable in terms of wellness and young kids. Well, everybody needs sleep. But for young kids especially because they're growing, we want to promote that they get at least eight hours of sleep per day. And so these devices also measure the hours of sleep for an individual.

The bottom two snapshots there are what the polar loop can do. The polar loop goes 24 hours and it actually measures the type of physical activity that you had, whether it was moderate for example or if it was intense. And on this dial here, the darker the color the more intense the physical activity was. And if there is white space, that was where the individual was asleep, and on a 24-hour clock, it can break down all the variables that I mentioned above and aggregate on an individual basis. And so there is immediate feedback. We're looking right now to see that this will motivate and maintain the physical activity education that we're giving to the youth, and so far, it's been quite positive. All the data that we collect, we give copies back to the parents, back to the community partners, a record of the different -- like for example the glucose, the waist circumference, the blood pressure, all of that is actually placed

in the medical charts of the youth. And then as referrals are necessary, those are made by our medical staff. And then we also recognize that the resources that are necessary may not always be available at the community level and that there is usually a multidisciplinary approach that is necessary to address the different things that we uncover at camp. And most of the times though, they're actually suspected already, but now we have data to support some of these things that really do need follow-up.

Some of the things that we're doing besides hosting the camp is doing all the things that we just mentioned is that we've been assessing the longitudinal data. As Dr. Joe said, this camp has been ongoing since '91, and so what I've been doing is looking at that historical data. In the slides that you see there, it's just data from 2011 to 2014 where we've put in all the data on the BMI's. And from this really quick shot, you can see that the red line is at the 96 percentile and many of our kids, both boys and girls, are falling above that. Again, there is that again underscoring of the urgent need for us to be intervening on these now.

And then we're also working to follow up with the youth for six months after camp to really again make sure that they maintain the different things that we've taught them and that they are incorporating these lessons learned working with their families and with their parents. And then this coming summer, we're going to be including 24-hour dietary recalls with our program. And then again, we'll be including the parents in the education and involving health coaches and we continue to write grants to support all these different initiatives that we're describing. And so, I will turn it back over to Dr. Joe.

Jennie Joe:

Well I think there's no doubt about the fact that we need to do more in taking a real serious look about utilizing various biomarkers. And this is an old data set here but it does bring back that message. This is a sample of 4,753 Pima children that was measured between 1965 and 1998. What they found in that first sample was a hundred of the children had already been diagnosed with type 2 diabetes. Five-hundred and forty-eight had impaired glucose tolerance and a little bit over 4,000 had normal glucose levels.

When you went back 10 years later, the interesting thing about that is a hundred and sixty-nine or 11% of the children who had normal glucose developed type 2 diabetes. I think if you weren't paying attention to this and did not see there's a possible risk factor, you would assume that this wasn't going to change, but it does. And a lot of it has to do of course with the fact that as kids develop, they eat more and what they eat makes a big difference on whether it's healthy or not. And their sedentary lifestyle increases in many places. And I think a lot has to do with the fact that we, as Native people, don't really emphasize physical activity as an activity by itself. I think we have grown up in an environment where you're out there, you're digging the soil or what have you working on your farm or maybe you're out there riding horses, gathering the horses to take them to the water or all these kinds of things were really work-related and they were not categories that fall under physical activity. What we have now is society that spends a lot of time sitting and increasing numbers -- the kids now carry around all these technology gadgets like Kindle and increases the number of hours that they really aren't very active.

The 241 out of the sample that had impaired glucose tolerance also develop type 2 diabetes. So I think we just want to stress the fact that if you have data that you want to really utilize them. I think many communities now just do BMIs, and some of them do some measurement for hypertension. And I think we really need to do a little bit more and I think there needs to be some sort of effort that is included maybe at the annual school physicals that are required now with the school system. I think that might be one way to sort of broaden that need for looking at various types of biomarkers that are important.

This is really just to kind of bring back that point. The question, of course, is now that we're coming sort of close to the end of the hour is to ask the question, are we doing enough? And I think that we are doing a lot more than what was happening in 1990 or 1991. People have much more interest and are

much more involved in variety of physical activities. We have the wellness centers that are available and I think it's one of those things that happens; but increasingly, you see more adults at those facilities than you do young people. I think there needs to be an equal focus getting young people and involving them in variety of different things that would be attractive to them because we have to do more than just what is happening at school. The kid who plays basketball is on the basketball team. But there's a child over here who really needs to also be physically active that can't probably be in competition in sports like basketball.

So the other kinds of things I think is that we are really doing much more where ever we can, I think the emphasis on obesity prevention is important. I think that it's a problem internationally almost everywhere. One of the first conferences that we did on adolescence, we had people from Japan, for instance, where you would think because of the dietary rituals and those kinds of things in their country, they wouldn't have that problem, but they do. And in other society, it's just primarily type 1 in one of the new data that's being looked at is trying to find out where in the DNA structure is something going wrong that in this particular community, the Norwegian community and for example, are they getting so many more children with type 1 diabetes.

So there are still a lot of unanswered questions, but we are trying to take a look at how to prevent it and I think that these are commendable. There are other programs that we don't have time to really discuss. We do know that the Oklahoma Native Youth Preventing Diabetes is a program that also started in early 2000 and they have children and youth over age 12. And they do collect some biomarkers. I don't know enough about the program to tell you how those get utilized. But biomarkers have importance in the clinical arena so there has to be an open communication between what's happening in the prevention arena and where the clinicians can follow through these kids and maybe try to do something early enough to prevent some of these things. And also to make it kind of common practice if a child comes in for any kind of clinical visit is really to do some measurements because I think at one point or another, those are going to become very important.

And again, there are different types of camp programs. There's family camp, there are day camps and residential camp is the one that's also being used by Oklahoma. And they move their camp from one Tribal community to another community each year. And pretty much are non-profit organizations so they also have to raise money and find resources to sponsor their camp activity. And I think it's important that these kinds of efforts are underway.

I think some of the other things that really needs to happen in the larger scheme of things is really to develop a standardized kinds of program that really ties some of the data that we're doing more than just BMI. And I think we need to be able to do this in a way that we can understand that this is one place that we can intervene or maybe emphasize our prevention program.

I think there is a need for models and I think that we really need to take a look at children and young people with type 2 diabetes. So the important part of it is that we need to pay attention to how much children already know. We're doing a lot of work now with adults with the health literacy for example. There is a short version for young people. The new vital sign that is being used for adults that takes a label from ice cream and tries to figure out if the patient understands grams and how much ice cream can they get on a certain kind of limited diet. These are the kinds of things that maybe a little bit more complicated for young people and it's certainly very complicated for our elders. We really need to take these challenges on, put those out there, let's start thinking outside the box and make it useful so that we can make it relevant to the communities that we work with and are concerned with.

I think we also really need to remember again the whole idea of youth culture and Tribal culture. I was working on a project once in South Dakota. And the children in this program had a lot of exposure to Sioux cultural activities, everything from Sun Dance to sweat music. But the parents were saying to me, "We weren't raised that way. We don't know how to help our kids. When they talk about Sun Dance, we don't know what all that means because in our particular generation, we were raised in

residential schools that were run by various Christian organizations. And so those were taboo for us.” And so there is a disconnect between the idea of making something culturally relevant and assuming that parents know. So we really need to know a little bit more about our communities and to what extent these kinds of things are still part of their life and are important part of their cultural heritage.

Other things that are really important I think with young people as well as with adults is all the co-morbidity and a lot of it has to focus on depression. There are scales out there. As you all know, there is a shortened one that the CDC has for young people. One of the things is that you measure it but you got to have resources to do something about it. I think it’s just writing down the score doesn’t do it. You have to be able to meet that particular need. I think that’s very important.

Family environment is also a critical part that we need to remember. Many of the children come from stressful family situation and sometimes it’s always not safe. But we need to understand that that has an impact on their health as well. So I think we allow in this camp for kids to be children, to be youth, to be young people. And make it so that what they have to learn about themselves and their health is reinforced in a friendly learning environment. And I think that residential program offers that kind of thing. And it does really make it possible for them to not only understand they’re not the only one with a problem, but they have a network of other resources and other colleagues or maybe want to call them peers that they can share with. At the end of camp, everybody is getting each other’s addresses, telephone numbers, and some of them are crying because they don’t want to go home. That speaks I think to a great extent the kinds of rapport and the kind of strong network building that happens in this kind of a friendly environment that makes culture very important part of that environment.

That sort of concludes our pony show. I’ve seen a lot of questions there and I think we may have covered some of this in the process and as Francine says some of these materials are available. In this last slide, you see our contact email and when it comes to the curriculum and those kinds of things, Francine is the person to make contact with, you can communicate with her directly.