Decision-Making Steering Committee Speaker Series:
Dr. Jeannine Brant
July 30

00:00:00 AMOLA SURYA: That good with you?

00:00:02 DR. JEANNINE BRANT: That sounds great. Thank you.

00:00:04 AMOLA SURYA: Okay. Good afternoon, and thank you for participating in the decision-making steering committee speaker series. My name is Amola Surya, and I will be moderating today's webinar. I'd like to introduce this afternoon's speaker, Dr. Jeannine Brant, oncology CNS and nurse scientist of the Billings Clinic. Dr. Brant will discuss her personal experience as a practitioner and what she identifiers as most challenging issues in cancer prevention and treatment. At this time, all participants will be in listen-only mode.

00:00:39 Please note that this webinar is being recorded. If you have any technical difficulties or questions, please enter your question in the chat window so we may help you. I will now turn the call over to Dr. Brant.

00:00:54 DR. JEANNINE BRANT: Great. Thank you so much, and I just want to thank you for the opportunity to kinda

share some of my experiences in my work. And I work in a lot of different capacities, and so I had to kinda choose which area to focus. I'm hospital and clinic space, but I also have a large practice in our rural community and have a long history of working with our American-Indian population. And so when we get to the discussion point, we could certainly talk about other issues including, you know, the rural challenges that we face in Montana.

00:01:29 It's such a large and (unint.) populated state, but today I'm gonna talk about our cancer control in our Montana's American-Indian population. So go to the next slide, please. So just a little bit about Montana, we are the fourth largest state and yet we're the 47th in population. In fact, in our 2000 census, we almost to a million people that year, so you can see how few people we have. A little over 6% of our population is American-Indian.

00:02:01 And on the next slide, I think you'll see the map of the state. We have, again, a fairly large state. We have seven American-Indian reservations represented by about 12 tribes in the state. Two of the largest are

next to Billings where I live. Billings is Montana's largest city. We have a little over 100,000 people in our population, but our area's about 150,000. Just a couple of things, demographically about what's happening as well is our state is changing with the Bakken oil boom in the eastern part of the state in North Dakota and on the border.

00:02:41 In fact, a lot of our America-Indians are going over there to work, and it's providing good income. But it's also, again, changing the landscape of Montana, but you can see we have seven reservations. And then we also have urban Indian clinics in some of our major cities where our patients go. So next slide. Interestingly, cancer is the number one cause of death in our Montana's American-Indian population, and that swing happened about two years ago.

00:03:15 And these data are very difficult to find, and that's one of the challenges we have in our research is looking at the census data and trying to get a good grasp on, you know, the population. Statistics can be challenging because there's a lot of shame associated with the (unint.), and so a lot of times we'll go to

the IHS data and other reports to really find these trends. But we do recognize that cancer is now the number one cause of death (unint.).

00:03:48 You can see with non-Hispanic whites in Montana, the rates compared to our Montana Indian rates are 5 … 35.1. The types of cancer look basically the same. Patients, of course, are diagnosed in later stages with the disease, so survival is really impacted. And also, patients are diagnosed much earlier with disease. For example, breast cancer occurs much earlier in these American-Indian women, and there are a couple of papers out there proposing some unique genetic variables within the population.

00:04:21 Next slide. Of course, the lifestyle and personal factors really contribute to the high incidents of cancer. Over half of the adult American-Indians in Montana smoke, and when you start looking at the issues surrounding this, it's interesting that the reservations are where people go to buy cigarettes. Cigarettes are extremely inexpensive on the reservation. And of course, that can contribute to some of the rates that they see.

00:04:54 We also see a lot of obesity, and some of my research partners focus a lot on this issue. With lifestyle wellness, diabetes prevention program, we're looking at teaming together some of our cancer prevention and wellness programs overall. But we see a lot of childhood obesity as well. In fact, I was just in, like … up in the cafeteria, and I saw an American-Indian family up there, at the grill. And we … all children, even our four-year-olds, are very obese.

00:05:25 It's quite sad. With that, there's an increase in type 2 diabetes in children. We also see about 30% live below the poverty level in some of the reservations. Next slide. So I started working with the population in 1990. I'm actually from Montana and then went and did a Master's Degree at UC San Francisco and spent some time in California. And then I moved back in 1990, and a couple of the things that really stand out for me as far as working with the population is the trust relationship.

00:06:03 And that's in everything we do. It's very difficult to start work in this area, and then once you develop

trust within one group, a lot of times the leadership can change very quickly. And so then redeveloping trust and establishing relationships are really pivotal to the work that we do. Being visible is also a theme I'll use throughout. I think in order to be successful we have to have visibility in these communities.

00:06:33 It has to be the same person, you know, the same team of (unint.) and just a constant presence and reminder that you're there, that you're there for them and that, you know, we're working on things together in a good relationship. The next slide. So the way that I got started in this area is I was a young clinical nurse specialist, moved back to Montana, and we actually had a grant through the National Cancer Institute to try to recruit patients to clinical trials.

00:07:06 And what we noticed was that in the three years that they were out there … and this was right before I came … they had only accrued five American-Indian patients to clinical trials. And one of the outreach workers invited me to go to the reservation, and I took a

visit out there and just kinda had some good connections. I met some people who were really passionate about, you know, trying to talk about cancer and try to take a look at prevention and cancer control.

00:07:42 But, again, a lot of the people could not even say the word cancer. To say the word cancer would mean that they would bring it onto their people, and so if they can't talk about cancer, how are they going to do anything about it? After that time, I received a call from some home health nurses, and they had gotten a call from a family who said that their grandmother was smelling. And they went into the home, and of course, the grandmother had an ulcerated fungating breast mass that she did not want to talk about.

00:08:17 So all these things were kinda happening at once, very few mammograms being done. Fatalism was present, so we basically wrote some grants to try to provide some education out there on the reservation. We were funded through Avon and Susan Komen initially, and we had an educationally approach. We used a lot of different formats, and we really looked for people who

could be good representatives, tribal leaders, and found one woman who was a state legislator that was American-Indian who was a cancer survivor.

00:08:54 She really helped us a lot, but we did some nontraditional types of education. We centered things around art projects. We looked at the cultural types of educational activities that they would take part in, for example, making their dresses for a pow wow or a dress ceremony. We had generations of wellness parties. We tried to focus on anything that would promote some cultural networking along with cancer education. Next slide.

00:09:32 This is just … it's kind of an old picture, but I put it in there because we would do these cup art. And we would bring women together, and we would do an art project. So we had this cup art going. At the same time, we were trying to teach them about early detection of breast cancer, about breast self-examination, about mammography. Sometimes we would have screenings there. We would see them. We would offer them incentives, and we would talk about trying to stay well for generations to come.

00:10:04 We would even offer pictures where we would have four and five generations of women who would show up with their grandchildren and take photos and talk about wanting to live for generations to come. We had a full team. In fact, we've received throughout the years about $1 million in funding from a lot of different sources and really tried … again, it was an educational focus. We didn't have good measurement of our outcomes at this point but tried to be present in the population.

00:10:36 Next slide. We also received eventually funding through CDC through the breast and cervical health program. So we started screening women at all seven American-Indian reservations. Again, we offered incentives. Our screening rates really dramatically increased. I mean, I think we laid that foundation for education, and then we had that same team. We finally built to a team of four of us. We would travel over 20,000 miles a year.

00:11:07 We had a mammography van, and we were in a program that was really highly recognized in the state of

Montana with the Montana Healthcare Association's president's award one year that we won. And then nationally, we won a couple of awards as well for our efforts out there. Next slide. So the funding continued through the year, and again, we were responsible for screening American-Indian women both urban and on reservations.

00:11:37 Follow-up was a challenge. Even though women came and got screened, if there was a positive result, trying to get them in for a diagnostic mammogram and then biopsy … that continued to be a challenge. And we were … and this, again, was a while back. We were still plagued by the thought that there were a lot of women out there who once they found out they had an abnormal reading had a difficult time even coming back in for further screening. Again, gifts and food were offered at screenings and at all events.

00:12:11 And to not do so would be culturally inappropriate. In fact, everything we do out there … still, we offer food. We offer gifts, and it's part of who they are. Next slide. One of the things that we did was … early on, again, we recognized that people would not talk

about cancer for fear that it would bring them on to the people. So we wanted to show that cancer was the enemy, and we ended up producing this film called standing strong against the cancer enemy.

00:12:48 I actually sat down with some pharmaceutical folks that I'd worked with on another project and asked them for the money over dinner one night. They gave us $20,000, and we produced this film with over 200 American-Indian tribe out, which was pretty amazing to us. We paid the actors. The gentleman that you see here. His name is Linwood Tall Bull, and initially, he told me he was not gonna do the project. He says, "I cannot do it because it's going to bring cancer to my people."

00:13:21 And then he called me a week later, and he said, "Too many of my people are dying needlessly from this disease. We have to do something." And so he was brave enough to stand … step forward, and he served as one of the tribal elders on the video project. We distributed over 400 copies. Nationally, we won several awards for the film. It's still available out there, and it's still a thing that we use because the

one thing that our American-Indians know how to do is (unint.) stand strong against the cancer enemy.

00:13:55 And what we tried to use is a message that, you know, their ancestors used to stand strong with all of the healthy things that they did, that it's this lifestyle that they've developed that's not consistent with who they are as a people. And they assisted us in writing the script. We had several leaders within the community that helped with this project. Next. Couple of other studies that we've done in the area. One was chronic pain.

00:14:26 We use the (unint.) as an intervention, and I'm a pain specialist. So I was a practitioner in this case where I saw patients at time one right on the reservation and time two and three via Telehealth. This really introduced me to some of the challenges in working in these types of studies is that nobody showed up for these visits. I ended up hiring a person on the reservation who actually had to coordinate all the visits. And we had a cancer clinic on the reservation as well at the time.

00:14:59 We had one of our outreach workers that actually called the patients. If they didn't arrive to the visit and, like, for my chronic pain studies they didn't arrive, I actually … we had somebody go out and pick them up because many of them can't drive to the clinic. They can't get, you know, to their appointment. They don't always necessarily recognize the importance of that, and then we did some interviews. One of the students from Yale University came to Montana and actually, qualitatively looked at the cancer pain experience in patients in Northern Cheyenne.

00:15:36 Next. So with that … that was quite a few years, and then more recently, we'll talk about the NCCCP program here at Billings Clinic. And again, we really had a strong presence on the reservations. We have several education programs that we have provided health fairs, cancer 101, which is a community new work program. Dr. Jude Cawa (ph.) from Mayo Clinic really developed that. And we continue to have screening events in multiple cities throughout the region. Next.

00:16:18 This is just some of the … this is a calendar that we provided, and we had poster contests, and that's been popular throughout. And, again, you can see the theme of overcoming the cancer enemy that started so long ago that has really tried to infiltrate the community and (unint.) message. And you can see that these are posters that kids are making who are going into the school systems as well to try to deliver this message. Next.

00:16:51 One of the other projects … and this poster was presented at a CDCC conference that many times one of the reservations will have an idea, and they will have a positive project that can be adopted by other reservations. So that's one of the advantages is this competitiveness that you feel from reservation to reservation. But we … it was launched for men by men facilitators to look at colorectal screening. They distributed kits. 70% were returned.

00:17:22 We had five positive results. We found two early stage cancers with this project, and it was so successful that we call it the Moccasin telegraph that carried this message. And now, it's being adopted by

other reservations. Next. So some of the themes throughout the work we do, prayer's instrumental in everything we do. Everything opens with prayer, whether it's education or health or anything. Use of traditional medicine is important to incorporate.

00:17:53 Oftentimes our traditional natives … we have to come and even bless medicines before patients will take them. Cancer … we turn the unspeakable into a speakable enemy and have tried to do that. So (unint.) is very prevalent still, complaints of pain, complaints of symptoms until they are late. Many patients don't know that a painless lump can be potentially dangerous, so they don't talk a lot. And that’s definitely prevalent.

00:18:25 Lot of fear of addiction as well, and of course, we know that our American-Indians have a genetic predisposition for substance abuse disorders. And that's one of the concerns in our pain and symptom management treatment as well. Next. So some of the challenges for research … trust, of course, must be earned. Everything that we conduct … in fact the last grant that we have submitted … this is difficult.

They want us to get complete (unint.) and tribal leadership approval prior to submission.

00:19:02 So we have to start very early. Sometimes we'll have to sit in the tribal leader's office the entire day to be able to meet with someone. We also have to involve IHS, and so there's a tribal and then Indian Health Service kind of competitiveness. People don't necessarily trust Indian Health Service, and so we have to work around the politics with this in trying to decide about who to engage. Well, most of the tribes are under Indian Health Service. Some are not, for example, Northern Cheyenne really trying to become more of a tribally directed reservation.

00:19:45 Readability continues to be a challenge. We validated some interments (unint.) facilitators critical to this acceptance, somebody who knows the community and the people, someone who has established credibility. But, again, then we have to coordinate from Billings or from one of the other sites to maintain contacts. And part of the challenge is that the individuals that we hire or work with on the reservation … they're really

from their nontraditional partners. And so they don't have PhDs.

00:20:19 Some of them have Master's degrees, and so I think the opportunity to work with some of these nontraditional partners needs to be considered. Recruiting patients … and, again, it's under trust. The need to give gifts … gender-specific sensitivities are critical for women to examine other women, men to examine other men. When we look at studies or interventional studies, that's really important as well and then retaining people in studies as well. Next slide.

00:20:56 So where are we going to go in the future? Well, we are now an NCORP. We just got funded last week. It wasn't as much as we had hoped for. There's a cancer care delivery research component within NCORP, if all of you aren't aware of that. We haven't seen the split out yet, but we're hoping to kind of include our American-Indian in our world research in the CCDR. But, again, this is hard to do having such a wide geographically disperse state with so few people and so little money.

00:21:31 So (unint.) of course we know is out there as well. We have palliative care navigation ideas for future efforts not only on our American-Indian reservations but also in our other rural areas. We have a supportive care team here that we are hoping to kind of use as a model to kinda reach out and infiltrate other areas of the state. I can say that when we've got together with the tribal leaders in our American-Indian leadership, we wanted to write some palliative care and symptom management grants.

00:22:06 They totally changed their focus, and their concern is really on cancer control. And, again, they say too many people are dying of cancer, and they're also seeing other diseases take off, like I said, type 2 diabetes in their children. And so they are really wanting to be engaged in cancer control research. Think that's my last slide. I'm not sure. Oh, just my references and other … some of the articles, so at this time I think we'll open for some discussion.

00:22:35 AMOLA SURYA: Thank you, Dr. Brant. At this time, I will now turn the call over to Dr. Jerry Suls, senior scientist at the Behavioral Research Program. As a

reminder, this webinar is being recorded. All lines will now be unmuted.

00:22:53 DR. JERRY SULS: Thank you. Dr. Brant, that was an … a very interesting and fascinating presentation, which we greatly appreciate. I'd like to ask you a couple questions at the top, and then I think others will probably chime in. Given our emphasis here in this context on decision-making, I'm wondering if you could say something about decision-making. We already know based on what you're presented that just the decision to be screened is something that requires considerable challenges in this population because of potential lack of trust and/or some of the stigma that is associated with cancer.

00:23:52 I'm wondering if you could say something about the decision-making process if there is a positive diagnosis. If something is found, and they're referred for care, how does the issues of cancer and the stigma, the shame, and the elements of trust interact with the decision-making that the patient does? And in particular, what might happen in the

decision-making between the physician, the healthcare professional and patient?

00:24:32 DR. JEANNINE BRANT: So I think things are changing, you know, and it definitely depends on the families, and we have a … you know, there's such variability in our families. And many times, there … it's usually collaborative decision-making (unint.) opportunity where oftentimes it's not just the patient who makes the decision about treatment, but it's the family as a whole. And it's not even a paternalistic where a husband will speak for a wife, but rather that it's a family decision together that they as a family.

00:25:09 And then they have very large families that might gather for that decision-making process, and uncles, kids, and are all considered brothers and sisters. So there is that joint decision-making there. For the shame and the stigma, yes, that's definitely still prevalent, and yet people are starting to talk about cancer more. We are starting to see some longer term survivors, which provide hope for the communities and hope for early detection and getting in sooner.

00:25:47 However, we still see a considerable amount of families who are lost to follow-up, and I would like to say that it's oftentimes reflective of what's … else is going on in that family. And with many of these families, substance use disorders … you can't not consider that. It's such a prevalent problem in the society, so it's almost like we need interventions that are going to address both. And the other piece is the early childhood trauma and traumatic events on the reservations, abuse, murder, sexual abuse.

00:26:35 These are all common themes on the reservation and in reservation (unint.), and depending on how functional the family is will depend on what their past is for cancer treatment. And we do have some incredible families that are stellar role models and tribal leaders that are getting screened. They're coming in for care. They're making good choices, but then we also have those who are living in poverty and have the problems that plague the reservations.

00:27:12 DR. JERRY SULS: Okay, thank you.

00:27:13 DR. JEANNINE BRANT: Does that answer your question.

00:27:15 DR. JERRY SULS: Yeah, that helps. I guess another question that's related to this, when you came back to Montana in 1990 to start working with these population, was it a surprise to you that the level of stigma or shame was as high as it was? Or was it something you already were familiar with?

00:27:42 DR. JEANNINE BRANT: You know, I was so young I probably didn't know. You know, I guess … well, I grew up with American-Indians, and you know, there was … there is some, you know, prejudice, for sure, with the population. But yeah, I would say that I was very surprised. Now I'm working with a lot of populations around the world. I've been spending time in the Middle East now, and you know, I guess the more I've learned about this, the more common that I see it is.

00:28:15 But yeah, I was shocked but also just … I was saddened because many of them really desire to get beyond this and to start talking about it. But it's almost like they have a foot in the right place and a foot that's really kinda sunk in tradition that says you shouldn't do it. And yet the challenge that we've had and we've

had a lot of consultants say this is that what they say is cultural is truly not cultural.

00:28:46 It's alcohol culture, and it's traumatic culture, which is not who they used to be as a people. And so … but yeah, I was definitely surprised, but again, I was pretty young at the time.

00:29:02 DR. JERRY SULS: So I want to follow-up on last … one of the last things you said. So the stigma and sham is not necessarily something you think that's linked to culture or folklore among this American-Indian tribe. Is that what you're saying?

00:29:27 DR. JEANNINE BRANT: That's actually what I'm saying, yeah. And I think a few people kind of swayed my thinking in that way. Even though we know that the … there was no word for cancer traditionally, you know, it's a … or it was a sore that does not heal. We know that people … they believe that they didn't have cancer in earlier times, but it's probably they just didn't know about it. So they believe it was something kinda brought to them.

00:29:59 But historical trauma really plays a part in who they are today, I think, as people. And it's that historical trauma that has really … and their genetic predisposition that's really led to some of substance use problems and the early childhood trauma issues that I believe is foundational to their lack of screening because it reflects how they feel about themselves individually.

00:30:33 And so the problem is not lack of knowledge necessarily. It's lack of self-esteem and self-worth and who they … what they contribute as individuals. And as we start working more with some of these populations … and we had a prison outreach as well because most of our women in prison in Montana are American-Indian. In fact, we found two cancers in prison when we were doing outreach there as well. But we … oftentimes, some of the things that are most instrumental in the population are workshops that kind of encourage who … they're valued as a human being and as a person.

00:31:19 DR. JERRY SULS: (unint.)

00:31:20 DR. JEANNINE BRANT: Which also means that we have to have very different interventions as we approach the population.

00:31:29 DR. JERRY SULS: Yeah, I was gonna ask you with respect to smoking, for example, which I assume is … probably there's a high rate of smoking … whether smoking cessation is something that's high priority, low priority, or is this something you haven't really … this is not something that you've directly been dealing with?

00:32:04 DR. JEANNINE BRANT: Smoking cessation … high priority. It's part of our message for sure. I think there are some things that we need to do. Like I said, over 54% smoke of American-Indian adults, and cigarettes are cheaper on the reservation that anywhere else in Montana. So politically, we've got to address the cost of cigarettes in Indian country, and the other thing is that we have to use, yes, nontraditional methods to … for smoking cessation.

00:32:40 We include it as part of our diabetes prevention program. We have included it in our education

outreach. It's always part of the message, but I'm not sure. And this is the other huge challenge with this area of research is documenting outcomes. So a lot of this work was when I had a Master's degree, and you know, I was just out trying to do the best we could. And we published a few articles, and we did a lot, but then we start thinking about how are we gonna document the outcomes?

00:33:10 And, you know, looking at NCI funding and CDPR community-based participatory research, this is where it gets difficult to write grants that meet these needs that's compelling enough to the funders but at the same time were able to do the work that's needed out there. But yeah, smoking cessation is gonna have to be huge because lung cancer's their number one killer as well.

00:33:46 And interestingly, you know, the reservations are dry in Montana. There's no alcohol, and so that's been, you know, fairly successful to try to help stop drinking on the reservation. It doesn't stop it, but it discourages it, but cigarettes … everybody smokes. And I think … the other belief that I have is that,

you know, the only … the way that we're going to work effectively with the American-Indian population is really engaging them. And, you know, part of positive deviance is that the answers exist somewhere in the community.

00:34:24 And we just have to go and find them and what … you know, what are some of the things that they want to do? But we have not attacked smoking specifically, I should say.

00:34:36 DR. JERRY SULS: In terms of trust, which seems like a … well, it seems like a vital component in all medical and public health interactions with patients, with communities. Are there any special things beyond what you've already said to try to engender trust? 'Cause obviously, with the latest emphasis on shared decision-making, that really is gonna require trust among the … between the parties or among the parties. The history obviously of the treatment of Native Americans leads for … obviously leads to a lot of mistrust.

00:35:25 But I wonder, are there any special ingredients in how to try to improve that situation to increase trust?

00:35:36 DR. JEANNINE BRANT: Yeah, those are all such great questions, and you know, it's kind of interesting because we had such a great deal of trust with our team. And I think it was … they can read your heart, and you have to definitely have the right heart going out there. And, you know, the … and you've seen historically in our researchers with an agenda for a CV they just don't make it out there. I hate to say that.

00:36:07 You have to have a lot of passion and desire to help the population, and they can see that clearly, first of all. Being an insider helps, but it does not really guarantee trust. We've had, you know, insiders from the community that have also failed. So having the right person is really critical to gaining success, being very careful because we've also had researchers who started doing well out there, and then if you just unintentionally do something a little different or don't ask them about something, then you have also lost trust.

00:36:52 I would say that the biggest opportunity for success is to really just establish trust with one of the tribal leaders who has a lot of credibility. And Linwood Tall Bull … the picture I showed you … he's … he was a medicine man on Northern Cheyenne. And it's almost like if you're in with Linwood, you're in with the Northern Cheyenne reservation. You know, if you're in with Kenny Smoker at Fort Peck, you're in with the reservation.

00:37:24 So finding these key people and getting them on your team and having these tribal leaders guide your research agenda I think is the most critical. So it's a tribal leader issue. Sadly, this is amazing. Kenny Smoker died a year after we started working with him. I've had two other workers die of cancer very early in their 40s who … they were on my early women reaching for wellness program. And also, people change. I mean, the tribal leadership is up and down.

00:38:09 But there are some stable people that are continued leaders, and they have a continued presence in their community. And those are the people to find.

00:38:21 DR. JERRY SULS: You mentioned before that was not uncommon when there was a diagnosis made and there needed to be some decisions that it's much more of a communal decision (unint.) other (unint.) … other … many family members etc. Would it be true that the tribal leader would also get involved in some of those cases?

00:38:51 DR. JEANNINE BRANT: Yes, that is pretty common, especially if they're part of that family or if they were asked to be involved, and not necessarily, because the tribal leader might be known. But then they may not be a part of that family, so they may not be involved. But if they're a medicine man, they might get called in, especially for the traditional native. So one of the things with the large groups, for example … if there's been a motor vehicle accident and we have a native person in our intensive care unit, it's not unusual to have 100 people around that and in those rooms.

00:39:38 Same thing happens with cancer. What we're starting to see … sadly enough is we're starting to see more

abandonment where, you know, they were really family-oriented and some still are, but we're also seeing because of the distance … like, we had a 27-year-old gal with advanced cancer. It was an advanced (unint.) lung, and she didn't even smoke. It was very sad situation, but she lived way out. And Northern Cheyenne … it's a good four-hour drive from here.

00:40:13 And she had nobody at her bedside, so it kinda varies, but for the first decisions, yes, usually, it's a group that helps makes those decisions. I think another thing that's lacking is we do not have any clinics now on the reservation. All of our patients have to come to Billings to receive cancer care, and again, Crow Agency is about 90 minutes away. Northern Cheyenne is about three and a half hours away or three.

00:40:44 It's a long drive, and part of the barriers of why we're not out there … first of all, you have to be really patient provider because we'll have 20 patients scheduled, and maybe 10 will show up. We have to get somebody to help us to go pick patients up. You have to deal with Indian Health Service Clinic and the

records and how we keep records, and you know, we're more electronic now, which helps. But that would help care be more conducive to that family process, so that's a step we need to go toward.

00:41:22 Or telemedicine. Again, I think more telemedicine opportunities, and one of the grant ideas we had is to put a navigator out there on each of the reservations and then have that navigator meet with our symptom management team over telemedicine really talking about, you know, patient symptoms and unmet needs out there because that's my other big concern is that those already diagnosed with cancer are receiving substandard pain and symptom management out there because of the lack of resources.

00:42:02 DR. JERRY SULS: And I want to make sure that I don't dominate the questions, so let's give it a minute for some of the other people listening. But if they don't, I do have a couple of other questions I wanted to follow-up with you on. Okay, I guess … so you talked about palliative care navigation. I wonder if you could say something about the use of palliative care, the decision to have palliative care, symptom

management in the context of this (unint.) you also referred to.

00:42:43 DR. JEANNINE BRANT: Mm-hmm. So once diagnosed with cancer, I think it actually does open more opportunities to start talking about pain and symptoms. And yes, even like Charlie (unint.) work talks about, you know, some of his patients not coming in until their pain was a ten. We kinda see the same thing that they said they're out on the reservation. Their pain's a seven, and then they come in in a crisis.

00:43:15 Part of it might be stoicism, and (unint.) in my study did show a lot about them not talking a lot about it. A part of it's I think they're rural, and nobody's really assessing their symptoms on an ongoing basis. Now, they used to have more of a CHR program out there. Do you know what CHRs are?

00:43:37 DR. JERRY SULS: No, please tell me what that is.

00:43:39 DR. JEANNINE BRANT: That's a Community Health Representative, and these are tribal employees.

They're lay people who have some healthcare knowledge, and we've actually conducted training for them, too, because they actually go into the homes of patients who are sick. They do some data collection and report to the provider and tribal health nurses. And so we were using CHRs in that capacity, but that funding has kinda been up and down.

00:44:08 What we have really proposed, though, is if there's a nurse that could work with the diagnosed patients on the reservation. And you'd need a navigator on each reservation that could have a working list of patients who have cancer, you know, and to conduct a home visit because going into the home and specifically asking patients about their pain, you know, about their symptoms, about their sleep, and doing a full assessment will definitely yield, you know, more realistic data about what's going on in that family.

00:44:52 And then the other issues that come out, of course, are diversion, which … opioid diversion on the reservation is commonplace. And so trying to safeguard opioids in the home, trying to look out for all of these issues, but also having a team that

specializes in cancer care and pain, symptom management could be used as a consultative team for these patients out on the reservation. And that nurse navigator would be the liaison that would carry the message back and forth.

00:45:32 So that's kind of … you know, we've talked about that a lot 'cause we have a really high-functioning symptom management team here in our cancer center. We have the use of Telehealth, but that's, you know, as an expenses. We know that … and once we start talking to patients and you talk about the benefits of good pain and symptom management, a lot of times just having the discussion with them will really allow them to share their symptoms more openly, especially, you know, if they trust.

00:46:09 The other issues, though, again, are the patients hurting at home. You increase the med. You need to do a urine drug test because maybe the urine's gonna be empty because the patient … somebody's stealing her medications. I hate to talk about all these complex issues, but this is the reality of … those are all the things you have to look for in the home, you know,

having a navigator out there. But yeah, I think we could overcome a lot of the stoicism issues through that personal relationship with the patient, conversation, and really focus on the goals of quality of life, you know, increased function, decreased pain, and other symptoms, and time with family because they're truly a family-oriented society and lots of relatives to support you usually.

00:47:07 And so that's the focus. If we keep focused on those goals, I think we can accomplish what we need to.

00:47:14 DR. JERRY SULS: Okay. Do you find that one of the issues with regard to making decisions either between, you know, patients and the healthcare professional or with the patient and the family and other parties who are involved … where does the … where does tribal medicine fit in here? Is that something that ends up being an impediment, or really do they kind of … I'll call it our western medicine versus tribal medicine whether in fact they kind of live together at a reasonably … coexist … mutual coexisting?

00:48:06 You know, I think fewer people are using traditional medicine. Some ways it's sad because, you know, they're becoming more westernized, but I think it actually fits together okay. I mean, we allow the use of peyote, for example, and smoking peyote in the hospital and have to turn the fire alarms off. And smudging still occurs, the (unint.), the medicine man blessing medicines more so in the traditional older population.

00:48:38 The crow … both of our local tribes here have held onto their language, which is important, and so they kinda fit together. But, you know, I always think there's more that we can do to make sure that that is offered to the patients. And we try to do some things environmentally here as well like a special room for them. We have an American-Indian art throughout our organization, so hospitals do try to provide spaces for the traditional medicine to occur so it occurs some.

00:49:17 What usually happens, though, more often is that they receive their western medicine here, and then they go home and have their traditional medicine at home.

00:49:32 DR. JERRY SULS: Okay. So I think some people listening would probably say this is a very distinctive population. And their culture, their environment really probably interacts differently with decision-making. I guess I'm gonna ask you what might be a challenging question, which is that though they do seem very unique and distinctive, I'm wondering whether in fact some of these same themes actually apply to a variety of different parts of main stream North American culture with regard to how they relate to medical professionals, the cancer stigma and shame and things of that kind.

00:50:28 So I know I'm putting you on the spot, but I wonder do you have any thoughts about that?

00:50:34 DR. JEANNINE BRANT: I certainly do, and you know, when you think about decision-making and, you know, why people, you know, seek healthier options … and I do think that there's a lot of common themes here. And, you know, even though work … that you're probably aware of all the early childhood trauma work and, you know, how we're starting to see that score, that ACE

score, that Adverse Childhood Events score really impacts people's wellness, whether it's obesity, chronic disease, anxiety, chronic pain.

00:51:15 You know, and how people feel about themselves in general really influences their … and how they deal with stress and how they cope. That really influences the decisions people make about seeking preventive healthcare. And again, so to me, even though the message has to be educational at some point, that is not the foundation, I think, of why people make decisions.

00:51:48 And so I think our science has to really evolve to the point where we're looking deeper at the problems, you know, and even think about, you know, the family dynamics and again the substance use issues and all those types of things, I think, we really have to pay attention to as we move the science forward.

00:52:17 DR. JERRY SULS: Well, thank you very much. This has been a very informative conversation, and your presentation was excellent. We greatly appreciate your expertise, your special experience, and service

you're doing. So your participation here is very much appreciated. Thank you.

00:52:40 DR. JEANNINE BRANT: Well, thank you so much for the opportunity.

00:52:43 DR. JERRY SULS: You're welcome.

00:52:46 AMOLA SURYA: Thank you, Dr. Brant, for providing today's presentation. If you have questions after today's webinar, please email nci.brpwebinars@icfi.com or call 301-407-6608. Thank you for joining us. This concludes today's webinar. You may disconnect at this time.

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