



Conference Call Transcript

Q4 Bureau of Chronic Disease Prevention Cultural Competency in Diabetes Care Teleconference
January 28, 2004 12:30 p.m. ET

CORPORATE PARTICIPANTS

Dr. Leonard Jack
Tisha Crews Keller

CONFERENCE PARTICIPANTS

Good afternoon and welcome, ladies and gentlemen, to the Cultural Competency in Diabetes Care teleconference. At this time I'd like to inform you that this conference is being recorded and that all participants are in a listen-only mode. At the request of the company, we will open the conference up for questions and answers after the presentation. I will now turn the conference over to Tisha Keller. Please go ahead.

Tisha Keller

Over the past 50 years, ethnic minorities have carried the burden of most chronic diseases. The reasons for which this is true include genetic predisposition, food choices, lack of physical activity and cultural beliefs. And oftentimes, these reasons are overlooked in the diabetes education component of care. Diabetes educators, their organizations and collaborating partners should understand the roles that culture and ethnicity play in the delivery and receptivity of diabetes care. During today's program, we will discuss the code of ethics for diabetes, education, definitions of racism and many aspects of cultural sensitivity. Specific guidelines about healthcare service delivery will be covered to help each of you to make certain your diverse patients are offered full, equal health services. Our speaker, Dr. Leonard Jack, is a Senior Behavioral Scientist for community based research at the Centers for Disease Control and Prevention, Division of Diabetes Translation, at the Center for Disease Control and Prevention. He holds a Ph.D. in Health Education from Penn State University and has extensive experience in community intervention. Dr. Jack serves as an adjunct professor at the Morehouse School of Medicine in Atlanta and also taught at Howard University in Washington DC. He has over 20 peer-reviewed articles in publication, with topics ranging from bio to psychosocial factors effecting metabolic control to media campaign effectiveness. Dr. Jack is well-sought after for speaking and teaching engagements and is a member of numerous editorial boards and review committees. We are delighted to have Dr. Jack with us today. Please join me in welcoming Dr. Jack to this teleconference.

PRESENTATION

Operator



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The Big Bend Area Health Education Center approved this program for one contact hour, Nursing Provider FBN 2654. Nurses who want to receive CE credit must sign in on the sign-in sheet provided and provide his or her license number. In order to get CE credit, nurses must also complete two forms provided by the DOH. First is AHEC program registration forms and second is the Florida AHEC Network Impact Survey. Each site administrator should send a sign-in sheet and completed forms to Tisha Crews Keller, Florida Department of Health, 4052 Bald Cypress Way, Mail Bin A, as in Adam, 18, Tallahassee, Florida, 32399, by February 12. You may also fax the completed forms to 850-414-6625. CE credit will not be issued to participants who have not signed in, provided their license number and completed the required forms.

In addition, the Commission on Dietetic Registration approved this program for one contact hour at Level III for RD's and DTR's, provider number GG187. In order to get CE credit, dietitians must also complete two forms provided by the DOH, first is a continuing professional education reporting form, second the Florida AHEC Network Impact Survey. If there are no RD's and DTR's in attendance, please return the reporting form and indicated 'no RD's and DTR's attended' at the top. Each site administrator should send the sign-in sheet, the completed forms to Tisha Crews Keller, by February 12th. Dietetic Practitioners who are under the professional development portfolio process should not sign the reporting forms. These individuals should report this activity on their Step IV Learning Activity Log. Please refer to the flyer sent with the Continuing Professional Education reporting form for more information. The Big Bend AHEC will issue nurses who receive CE credit a certificate of participation. And the Diabetes Prevention and Control Program will send dietitians who receive credit a certificate. Dr. Jack, I'll now turn the call over to you.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Thank you, Tricia, and hello to everyone. I know that you can hear me. I'm really excited to share with you some of my thoughts and thoughts of some

of my colleagues here at CDC around the issue of cultural competency in diabetes care. I want to bring to your attention first a couple of documents that you should have already printed off and have had a chance to read. If not, we will certainly cover a good bit of the information contained in these two documents. And those two documents, the first of which is entitled 'Cultural Sensitivity: Definition, Application and Recommendation for Diabetes Educators', which was published in the 'Diabetes Educator'. It is an official position statement for the American Association of Diabetes Educators. Also you were provided with another article entitled 'Race, Ethnicity and Diabetes Care: Where to From Here'. And publication was also published in the "Diabetes Educator". Hopefully you had a chance to read those two publications. I would use these two publications as a foundation for my discussion today. But I must be honest with you, I will interject other readings, other bits of literature, some experiences in my discussion today. So if you find that I'm sharing some information with you that you don't find presented in those two articles, please bear with me as I kind of talk and share with you.

Let me thank Tricia Crews Keller of the Florida Department of Prevention and Control Program, for coordinating this call. I can tell everyone, she has been very diligent in making sure that she has coordinated this call with my very, very busy schedule. Numerous emails, telephone calls, so hat's off to Tricia for making this all happen. And thanks to each of you for giving up some of your time during lunch or perhaps all of your lunch today to be with me as I share with you.

I have a few expectations for this call today. My job, over the next hour, is a tremendous one. I understand that my colleague was not able to be a part of the conference call due to inclement weather and I hope to take full advantage of the time. But I have a huge task ahead of me. As we talk about cultural competency in diabetes care, I need you to keep a couple of things in mind. That first, the body of literature around the role of culture in health is simply enormous. And this body of literature is growing rapidly. Therefore, it will be impossible for me over the next few minutes to convey the breadth and the depth of that literature in research and practice in the field of diabetes care. It simply would



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be impossible. So my primary goal, over the next few minutes is to perhaps just encourage us all to think about this important topic, share at a minimum some of the things that we believe are important considerations as they relate to diabetes care. By fostering this dialogue, I'm hoping that it will challenge us to be at a different place, at least at a minimum, at the end of this conversation.

On today's call, I recognize there are a diverse group of disciplines in individuals. We have diabetes educators, we have dietitians, we have health educators, have program planners, hospital administrators, behavior scientists, members or representatives from community-based organizations, clinicians and the list simply goes on. So again, I am sure that I'm going to present some information that is familiar to some of you and some of you will not be familiar. But again, regardless of what I'm going to share today, I'm hoping that we will learn something new or reaffirm the need to put into practice what we already know.

The learning objectives were presented to you briefly by Tricia earlier, but I want to go through them, because I'm going to at some point deviate from them. And there were five that were provided to you prior to this conference call. The first one was to discuss social determinants of health in minorities. The second one was to define at least three elements of respect in diabetes education. The third one was have working definitions of racism and ethnicity. The fourth objective was to recognize the difference between surface structure and deep structure within the context of cultural sensitivity. And the fifth objective was to identify implications for cultural sensitivity in diabetes care. Please note that I will try to address all these objectives. Some of them I may not get to directly but the information is contained there in these two articles or we may get to them at the question and answer portion at the very end of my discussion.

With all that being said, let me start this important topic of cultural competency in diabetes care. In order to set the stage, I wanted to talk about several reasons why this topic is very important, the topic of cultural competency in diabetes care. First, the debate in public health circles around the revolving explanation of how we can use cultural factors to

help us explain determinants of health behaviors. And there has been ongoing discussion for many, many decades as to why this is important. So today's topic and conversation around cultural competency fits right in line with current debates in public health around its importance.

Also, we know that chronic diseases, diabetes being one them, cardiovascular disease, hypertension, cancer, HIV and AIDS, have all increased in major proportions in the United States, which creates the challenge of us understanding how diseases and illnesses are manifested and are understood by individuals, their families and the healthcare systems, those providers, who are attempting to interact with these individuals who are experiencing the increased burden of these chronic diseases.

Third reason, according to all the latest figures, CDC puts out a fact sheet and it notes that minority populations in the United States have been frequently found to experience an excess burden of those chronic diseases that I just mentioned, diabetes, cardiovascular disease, etc. And so diabetes is now considered a major chronic health condition among African Americans, Hispanics, Asian Americans, Native Americans and American Indians.

And finally, the fourth reason why this topic is very important is that the US Census data contends that between 1990 and 2000, the total number of minority population has increased by 36 percent. And that these culturally diverse populations will comprise more than 50 percent of the population in 25 cities, major cities, numerous counties and the State of California. These increases, of course, will place additional demands on the public health system, on healthcare systems and, as a result, a very aggressive public health response is needed to deal with the increased number of minorities in the United States. That will also bring with it an increased number of minorities who will experience chronic disease, particularly diabetes.

I talked a little bit about race and I talked, of course, saying that among those racial and ethnic groups we have in the United States, those populations experience a disproportionate burden of diabetes in the United States. And that's a no-brainer. We all know that. But can race alone explain the disparity.





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And there are other postulates that have been generated that help to explain why there is a disproportionate burden of diabetes among minority populations. And they include one of five reasons. One, genetic predisposition. Two, family history. Three, food choices, dietary, lifestyle practices. Limited physical activity. And five, the interplay between all the previously mentioned factors. They all play a very important part in helping us to understand why minority populations experience a disproportionate burden of diabetes. Now depending on where your orientation and your training, your discipline may take you, you may be aimed to deal with one of these factors more so than the other. But in general, we all know that collectively these factors play a huge part in helping to explain the disproportionate burden of diabetes among minorities, or to general population – every in general, OK?

Of important consideration, however, is how our lifestyle practices, such as diet and exercise, are influenced by the setting in which they occur. By me saying that, I want to throw out and discuss two important settings or environments before I move further in my discussion about cultural competency in diabetes care. Physical environment – When I make reference to physical environment during my discussion, I want you to just sort of envision the last time you went out to a nice restaurant. I'm talking about the settings where lifestyle behaviors occur. For example, a restaurant, and determine whether or not that restaurant serves healthy foods. Walking trails, if they are available in certain neighborhoods. And safe environments or neighborhoods where walking is actually possible. In terms of the social environment, since we're talking about cultural context, I will use the term social environment throughout my discussion and when I make reference to social environment, I want you think about context within families, the work place and social support networks. OK? So it's important that we consider not only those factors I mentioned before, genetic predisposition, family history, food choices, etc., I want to also embed those kinds of factors within the context of social and physical environments. And without having those kind of environments distinguished, it would be very difficult to move the discussion further as I begin to talk about what is or

how are we going to define cultural competency at a later point in my presentation.

So we can draw a couple of important observations when we consider the role of these two important settings, the physical and social environment. First, they both occur outside the physician or healthcare setting where the focus is largely in those settings, in those clinical or healthcare settings on a patient's internal environment. By that, I mean, the focus is largely on hemoglobin A1C, blood pressure, cholesterol, blood glucose, tryglicerides and pharmacological interventions that patients are asked to follow in a recommended regimen. OK? The patient's internal environment is largely the focus in a physician's or healthcare setting environment.

And two, understanding more about these settings, and I'm moving back to the physical and social settings, understanding more about these two settings, will move us into a place where we can understand more about life experiences among racial and ethnic groups in the United States. These two settings, or environments, help to shape similarities and life experiences that either directly or indirectly impacts one's ability to either adopt, maintain or sustain important lifestyle practices. I want to repeat that again. That these two settings, or environments, help to shape similarities and life experiences that either directly or indirectly impact one's ability to adopt, maintain, sustain and – and sustain important lifestyle practices. In other words, all of us, regardless of our racial and ethnic background, we cannot escape these two environments and that the impact of these two environment, how that plays out on our ability to adopt, maintain and sustain important lifestyle practices.

In the context of diabetes care, here is what this means. First, attention must be given to the patient's external social and physical environment. And why is that important? In an ideal world, a person with diabetes would be in direct contact with a clinic for 30 minutes every three months, approximately 0.02 percent of his or her time. Even in the ideal world, the patient would be exposed to external factors more than 90 percent of the time. In other words, once they leave the physician's or practitioner commission's office, they spend 99 percent of their time in the real world. External factors that include





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social support at work, home, aspects of patient/provider relationship and supportive communities, all are part of that 90 percent of the time. Patients with diabetes or any chronic disease, all day, every day, and those patients must manage their illness on a daily basis. At the end of the day, patients essentially at the bottom line, are in control, no matter what we as providers may say or suggest to patients, patients are in control of self-management. They're in control of making their own decisions. When patients leave a commission's office, leave the clinic or office, they can and they do veto recommendations a health provider may make.

Therefore, collaborative care management is recommended. We're saying that use of a partnership paradigm in this particular formula is absolutely essential. All right, and we need to give patients the credit that they are experts similar to the importance of the expertise of healthcare providers. It is estimated that 70 to 90 percent of all self-recognized episodes of sickness including diabetes are managed exclusively outside the perimeters of the formal healthcare setting. I'll read that again, because I thought that was shocking. I'd actually seen this quote in a couple of published research articles. An estimated 70 to 90 percent of all self-recognized episodes of sickness, and that includes diabetes, are managed exclusively outside of the perimeters of the formal healthcare setting. So that means that the patient's world is very important. And it needs to be understood. So I want to move the discussion in talking very broadly about the patient's world.

Contemporary medical practice has become increasingly disordinate [sic] or detached from the lay person's experience. For example, medicine aims at diagnosing and treating diseases, abnormalities in the structure or function of the body's organs and systems. Whereas a patient views health, when they're not feeling well, from an illness paradigm, an illness perspective. And that illness perspective is shaped by experiences of changes in their state of being, they're ability to function as a result of not feeling well or able to function. The human's experience of sickness is where a patient's focus comes from. Said another way, disease in the western medical paradigm is malfunctioning – is focused on malfunctioning and maladaptation of

biologic and psycho-physiologic processes in the individual, whereas illness represents personal, interpersonal, cultural reactions to disease or discomfort. Illness is shaped by cultural factors governing perception, labeling those illnesses, explanation of those illnesses and valuing the discomforting experiences generated from that illness, all of which are embedded in the cultural and complex family social and cultural nuances of a particular race or ethnic group.

Because illness is experienced at an intimate level, it is very difficult to detach illness from social systems of meaning. And these social systems I need to share with you, help to establish rules for behavior, rules on how to manage that particular illness, rules on when you seek healthcare, how long you seek healthcare, etc., etc. It is strongly, strongly influenced by cultural. Illness, bottom line, is therefore culturally constructed. Very important to keep in mind that illness is culturally instructed. In other words, because all of us, regardless of our racial and/or ethnic background, we are shaped by our cultural experience, our cultural history, regardless if you are considered a part of a minority group or not, we all have a cultural and we're all shaped by that culture. We attach particular sickness labels to our illness based on our cultural background.

For example, for African Americans who have been diagnosed with diabetes, the labels that are attached to the sickness may be something like, a touch of sugar, sweet blood or having sugar. We choose how we respond to these labels based on our cultural background. We then decide how we communicate our health illness to other people based on our background. We also then decide when and to whom we seek for help. We also decide how long we will remain in care based on this cultural background. We also evaluate the care that we receive from this perspective. And then more importantly, we decided whether or not we will remain in care, whether we will seek care in a similar location in the future or whether we would continue a recommended regimen that has been proposed to us based on this cultural background. So incorporating aspects of culture in the design, delivery and evaluation of effective diabetes care is absolutely, critically essential.





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And I want to pause here and say that the importance of stepping outside of our comfort zone to learn more about the role of culture may mean, for example, participating in more conference calls or training similar to this. It may mean actually taking upon yourself to actually do some reading in the area. It could mean actually doing something as simple as having what I call cross-cultural conversations with members who are working with you in the same work space to actually ask some questions. Not that each other's responses will be – could be, for example, held to be the statement that all African Americans or all Hispanics would believe in or suggest that at all. But to open up dialogue across cultures so that we can begin to have a better understanding of how culture plays in our own individual decision making, which will help us to have a better picture of how culture plays a role in how our patients make health decisions. Again, keeping in mind that patients, at the end of the day, are the best managers of their health and make their own decisions. And they can and they do veto recommendations provided to them by providers.

So moving the conversation further to talk more about incorporating cultural characteristics in the design and delivery and evaluation of effective diabetes care. A couple things to point out. As I begin to have this discussion, I need you to always recognize that I will talk sometimes from two hats. One hat may be what can occur actually in a clinical setting between provider and patient. And then the other one is a more global, more public health perspective. And I'll talk about this later on in this presentation where I will share with you some of my observations in reviewing some studies that have looked at aspect of culture from interventions that have been delivered in community setting, OK?

With all that being said, I would like to talk about a place to start in diabetes care. Again, making reference to the publications that you were asked to read earlier, 'Cultural Sensitivity: Definition, Application and Recommendations for Diabetes Educators', you were asked to read that. In those – in that particular article, I provide a working definition for cultural sensitivity. The extent to which ethnic cultural characteristics, experiences, norms, values, behavior patterns and beliefs of a target population's relevant historical, environmental and social forces

are incorporated in the design, delivery and evaluation of health promotion materials and programs is how we define cultural sensitivity, is taking all those things in consideration when deciding to deliver effective one-on-one patient care or if you are trying to design an intervention that will be delivered either in the clinical environment, in a clinical setting or in a community setting.

We also extended and built upon this definition of cultural sensitivity by talking about two dimensions of cultural sensitivity. The first of which was surface structure, which we define and borrow from [unintelligible] Kyle and his colleagues, they defined it as matching, for example, printed materials and messages to observable, superficial characteristics of a population. In other words, if there are, for example, printed materials or brochures that has been developed, on the front cover of that brochure, if you're trying to target, for example, Native Americans, would be a picture of an individual who is Native American. In other words, -- and then also, if you are developing, for example video tapes, then those video tapes would have dialect and language that's appropriate for that particular population. And in most cases, the most effective way to do that is to do focus groups, to do field testing, to insure that those messages are not just generally trying to reach all Hispanics, but for example, targeting local areas and making sure that the dialect, that the way that they're dressed in videos or on printed material is very much suited to a specific geographic area, to make sure that those kind of idiosyncrasies are taken into account and made sure that they're represented in any printed material or videos or anything that's used for educational purposes.

Also, the setting is very, very important. There is a move to provide diabetes collaborative care in clinical settings, but also a move to have effective diabetes intervention delivered into community settings. And the setting is believed to play as important role as the printed materials or the educational video tapes, etc. It is believed that by going into settings where people are most familiar with and comfortable with, that this would somehow create levels of trust and increase adherence to the message and also in a way institutionalizing diabetes self-management where people live and play most of the time. OK?





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I want to briefly discuss with you some of the papers that were included in a recent systematic review that was conducted by Susan Norris. And I was a part of that systematic review. And the systematic review dealt with diabetes self-management education that has been delivered in community settings. And in that systematic review, there were eight studies that finally made the inclusion criteria and they use issues like if the study control for threats to internal validity, they looked at study design, they looked at whether or not the intervention was adequately described and/or if the intervention had an impact on certain outcomes. And those outcomes were bio-medical in nature. For example, if the intervention had an impact on hemoglobin A1C, glycemic control, tryglicerides, high blood pressure, cholesterol.

Out of the numerous studies that were screened for inclusion, eight of them made the final reporting in the systematic review. I'm pointing this out for a couple of reasons. That I went back and re-examined those same studies that were included in the systematic review. And in July of this year, a paper will be published in the *Annals of Internal Medicine* entitled 'Understanding the Environmental Issues in Diabetes Self-Management Education Research: A Re-examination of Eight Studies in Community-Based Settings'. In this re-examination, we were interested in learning a little bit more about the intervention. What made the intervention effective? We went back and we looked at the eight studies and found that six of the eight studies in fact targeted members of those minority groups that I mentioned earlier that are disproportionately affected by diabetes. So it led us to want to know more about how did those interventions insure that the interventions were culturally appropriate.

And in order to do that, we establish a criteria where we look for a couple of things. We look for whether or not the intervention was delivered in a setting that was familiar, and convenient to the target population to sort of increase its cultural appropriateness. And we also looked at this aspect of surface structure, where we looked at whether or not attempts were being made to insure that the educational material that was actually being used as part of the intervention or if they used a video tape, to insure

that those interventions were culturally relevant. And we found some very interesting things.

One, we found that 80 percent of the studies did not describe that aspect at all. OK. It would suggest to us that there were some elements that could explain around -- culture could explain why the intervention was effective. We just don't know specifically what they were. The studies that did give us some information about surface structure provided some very useful information. Some of the researchers went to the extent of including the participants in the actual design of the educational materials, as well as the actual being a part of the video tape and being active in the video tape itself, which helped to insure that the intervention was culturally relevant. And what we also looked at is to see if those interventions that were adequately described around cultural appropriateness had better outcomes than those studies that did not. And we in fact found that. That those studies that adequately described the extent to which they went to insure the educational materials met at minimum surface structure characteristics and that video tapes were also insured of surface structure characteristics that they were address, they showed some better outcomes.

For example, a study that was conducted by Brown in 1995, where she used video tapes that were developed with the use of participants from the target audience, in this case she was targeting Hispanics in Texas, that her outcomes were much more in depth. In other words, she had improvement in glycemic control, hemoglobin A1C was very, very good. So the whole notion of addressing cultural appropriateness is very, very important. The point I'm trying to make here is that often it's missed or its' not address. And it could be that in the studies that we re-examined that they had limited room to present that information in certain journals and that information could not be included because of word limitations, etc. But we feel that though it's very, very important. All right? So. The systematic review suggests that in the community, we could do a better job in insuring that cultural relevancy of our interventions are addressed.

Previously in my discussion, I talked about how all the decisions we make around health as it relates to our cultural background, just to refresh your memory,





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since I kind of deviated from the topic here, I mentioned that our cultural backgrounds helps to determine the labels that we attach to ourselves, whether or not we call it a touch of sugar, whether or not we have sweet blood or whatever we call that, as well as deciding how we communicate about our health and to whom and to whether or not we choose to seek help, etc., moves us into another dimension of cultural sensitivity, which would be deep structure, which determines the efficacy of a diabetes education program. For example, by paying close attention to how the illness is experienced. In this case, with diabetes, it is an intimate part of the patient's social system of meaning and their rules for behavior. So in other words, in order to get at how an individual will respond to diabetes, how long they will remain in care, if they choose to seek care, who do they choose to go and get the care from, is embedded in aspects of deep structure. I hope those two distinctions are very, very clear.

So this forces us surely to move beyond talking more than just saying race, whether or not an individual is Hispanic, whether or not they're African Americans or Native Americans or white American, it moves us to consider one's identity. In other words, the shared characteristics that are ancestral-based, characteristics that are geographically determined, that have cultural tradition in meaning, languages that help to identify one group's particular way of communicating over another, all these things play a huge part in how groups self-identify with a particular race. Those things are very important.

Also, let me point out, I'm having a good time here. Also let me point that there is a very, very good article that was published that talks about cultural identity. And one of the difficult things about cultural identity, and we talked about ethnicity here, is that if an individual feels as though they share characteristics that are common with other individuals, does that play a part in how people make health decisions. And there is an emerging body of literature that is beginning to look at that. For example, a paper that was recently published by Collins, Araham, Bouwa [sp], of Penn State and the article is entitled 'Cultural Identity in Health Lifestyles Among African Americans: A New Direction for Health'. And what he attempted to do in this article was first, to identify skills that have

been used to identify a core set of questions that can help individuals choose or select which ethnic group they most likely identify. But I want to read you some of these questions here because they have huge implications on some of the things I'm talking about.

I participate in cultural practices of my own group, such as, [unintelligible], special foods, music or customs. OK? I am very clear about the role of my ethnicity in my life. Another question here is, in order to learn more about my ethnic background, I have often talked to other people about my ethnic group. And he asked some additional questions is, I really have not spent more time trying to learn about the culture and history of my ethnic group. And these questions are being asked, let me frame it again, these questions are being asked in order to make the determination of whether or not the individuals identified with one group or another. Once those questions were asked, the data was analyzed to look to see whether or not if an individual, for example, more so self-identifies as being African American or Hispanic, what does that self-identification with that ethnic group have a role in playing or making lifestyle choices.

And in this particular study, individuals who self-identify more closely to being African American, when he looked at lifestyle practices, for example, eating traditional African American foods, when [unintelligible] are typically higher in saturated fats, he found that the higher or the more a person self-identified with being African American, based on the scale, looking at questions that range from one to four, and some of the mean scores on the questions are right at about four, when they were – when they self-identified as African Americans, those individuals had a tendency to eat more highly saturated foods, which suggests that where you are and how you are positioned in your ethnic and racial groups has a huge implication on how lifestyle practices are determined. And we all know that to be a fact. OK, so, and if you would like that, I can pass that information, this article on to Tricia and she can get that information out to you, OK? So we have two dimensions of culture, surface structure and deep structure. Both are important. The first is most often addressed. The latter is least often addressed. OK?





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I want to move the discussion now to into multicultural counseling and cultural tailoring, some of the terms that were presented in the article 'Cultural Sensitivity: Definition, Application and Recommendation'. And that can be found on page 923. So based on what I've shared with you so far, I hope that I've established that there is a perspective in being a patient that is different from the perspective, that is, of being a provider or a person who is offering care. And the patient offers, what I'm going to now shift and call 'the patient model' and the provider will offer what I'm going to refer to as 'the clinician model'. Both models essentially must contend and deal with five issues. The first of which, the patient will deal with the cause of diabetes. They're going to frame this thing from their own context. The patient will deal with what caused the disease and the clinician will deal with the etiology. Two, first signs of illness, and that's what the patient will contend with and the onset of symptoms is what the provider will deal with. What I'm just generally presenting to you is the viewpoint or the perspective that each of these two important individuals or entities hold. I presented to you how the patient would see it and I'm presenting to you how the clinician may see it. The third aspect is a change in one's body, feelings and interruption with everyday life is a perspective that the patient may view. And the provider or the clinician is looking at the patho-physiology of the disease. The fourth issue that either a patient or a provider must contend with, from the patient's perspective, they're concerned with what will happen as a result of having this illness. And the clinician will be concerned with the course of the disease. OK? And finally, the fifth aspect or fifth issue, both the patient and provider will be concerned with treatment.

Understanding the patient model is probably the most difficult thing for providers and clinicians to really get a handle on. In other words, it's important to elicit questions from the patient in order to understand more about how they interpret the illness from the context of their cultural background and experience. And I'm going to provide to you five questions that could be generated and used to frame that discussion with a patient.

The first of which is what do you think has caused your problem? And by asking this question, you're

allowing the individual to let you into their own experience around health. And it may mean that some of the things that the individual may suggest are not consistent with medical science. And that's OK. But having them to open up and share with you what do they think caused the problem, will also give you insight into some of the historical accounts of how diabetes has been dealt with within the context of family and how that plays into how that individual will receive a potential health message from a provider.

The second question is what do you think started this issue? OK? In other words, again, trying to get at, for example, whether or not they feel as though the cause of the issue is more from a spiritual context, if the cause was something that was a curse in some way or if the cause of diabetes, for example, was due to something that they ate over in abundance. Whatever the case may be, those things are worth exploring. And then ask the question, what do you think your sickness does to you? And then how does it work? By asking the question what do you think your sickness does to you, will give you insight into whether or not the individual feels that there is some opportunities for an intervention. If the individual feels that the sickness is something that has completely taken over their lives, diabetes is something that they've seen others have negative experiences around, and therefore there's nothing minimally that could be done, it may suggest a different form of intervention.

All right, the fourth question is how severe is your sickness? In asking an individual whether or not they think, for example, on a scale from one to five, one being least severe and five being most severe, finding out from their perspective how severe they perceive their sickness to be, could inform next steps in providing some diabetes care to that individual.

And the fifth question is, what kind of treatment do you think should be received? And this is an important question because many of the articles that I'm reading is talking about alternative healthcare practices that some of the minority groups are vested in that are never disclosed in a one-on-one situation with a provider. But those remedies are being used and they're not [unintelligible] necessarily when a





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treatment is strategized between the provider and the patient.

So we're suggesting that these five questions are very, very important in trying to enlist some understanding from the patient as to how they see diabetes. And that will take you into some of the issues of deep structures that I mentioned before. And these questions can be framed in a way that's appropriate for the setting, for the group that you're talking with. And that the most important thing is to be in a listening mode and not to pass judgment, no matter what is being said back to the provider. So a collaborative care approach is optimal in this case, which is different from the traditional care approach that is still in common practice today. And that is a patient comes in with his or her deep structure or surface structural experience and they have a perspective on how they view diabetes. Despite that, it's never acknowledged. It's never -- There are no inquiries into that reality. What is being provided is a regimen or how they believe that the patient should take care of their diabetes. And all of that is missed in the collaborative care process. So the traditional model is not necessarily the model that is being endorsed now. More of a collaborative care model, OK?

So, I want us all to remember is that patients can and will veto recommendations. So the goal is to remain a therapeutic ally when you're dealing with patients. For example, if the patient agrees to take his or her insulin but also insists on eating traditional foods that may be high in saturated fats, or processed foods, foods that may be dense in calories and the calories are high in fat or sugar, in other words, if the patient agrees to take his or her insulin but also insists to continue eating these traditional foods, but in moderation, we would say that that would be acceptable and offer an opportunity to talk about what is moderation. And then ask, from their perspective what does moderation mean to them. Because from a family context, cutting back on food means different things in a social environment where people tend to gather and eat, it has different meaning which is quite common that it's different from what, for example, the American Dietetic Association would recommend a portion size to be. So having some dialogue around what is considered moderation would give you some insight into how the family

network defines moderation, when it comes to food and in what settings and under what conditions and occasions are those moderations quote/unquote guidelines changed or varied.

However, let me give you another example. If a patient agrees to take his or her insulin as recommended but insists they will continue eat as they did prior to the visit, the commission will still need to find ways to negotiate with this patient. This is different from the first scenario. The latter scenario, the patient is saying I agree on one hand to take the insulin, but I'm also letting you know up front that I do not intend to change how I've been eating. So therein lies an opportunity for further negotiation. The process of negotiation is the single most important strategy to engaging patients [unintelligible] major discrepancies in the evaluation and therapeutic outcome, promoting compliance and reducing patient dissatisfaction. The negotiation must take place in order to gain a sense of understanding the patient's family, their social context. One needs to collect some cultural data, as I'm going phrase this, about the individual's personal and interpersonal environment. It's very, very important. And to find a way to meet somewhere in the middle and know that sometimes in the middle may not be necessarily what the provider optimally thinks is best.

The article that talks about racism -- 'Race, Ethnicity Diabetes and Care' was written in response to an article that was printed a month before we generated this one. And I think I want to talk a little bit about the whole aspect of racism. You heard me talk about culture and its really very important role in diabetes care. And without having a discussion on racism, I think we will miss some opportunities and challenge ourselves to look at how we do business. In this commentary, 'Race, Ethnicity and Diabetes Care: Where Do We Go To From Here', we tried to make the argument that even though we are trained as health professionals to be attentive to the needs of patients and the general public around diabetes care, there are opportunities on an individual level that we have to challenge whether or not we are A- open to our behaviors and our thinking about one group over another. And in making that statement we need to accept the fact that we don't necessarily need to feel comfortable around that and that not one group is





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being, it will be my discussion here, isolated or chosen, I'm talking across the board, regardless of your ethnicity, how you choose to self-identify, there are always opportunities to improve upon how we view other groups. And that patients, when they're in our midst, they are very, very alert and can pick up on whether or not we have a true sensitivity to providing care to them that is optimal. And I want to give you a couple examples of how perceptions of racism manifest in a diabetes care scenario. And I'm going to give you an example from focus groups that we've conducted with an ongoing family center intervention research project that we have here at CDC.

Back about a year and a half ago, we conducted about nine focus groups in rural Georgia. We were interested in looking at whether or not this model we put together called an [unintelligible] model that examines social and contextual processes that help to explain how people make decisions in the context of [unintelligible] looking at routines, looking at family roles, how they communicate, etc. We asked questions around their adherence to recommendations from a provider. And we wanted to know what things in their opinion impeded their ability to adopt and implement those recommendations from a provider/patient perspective. We learned that some patients felt that they wouldn't – basically going to receive diabetes care to get their adjustments in insulin, but essentially some of them beyond that were not adhering to some of the other recommendations that were made. And we began to probe even deeper to ask questions around that.

They then mentioned to us that issues around racism to them were very paramount in their experience in healthcare environments. So having learned that, we asked some additional questions and we asked one basic question, why do you feel as though the experience to you minimized you as an individual being a part of one particular ethnic group. And in this case, we're talking about African American, males and females, who've been diagnosed with diabetes who are at least 45 years of age, who live in rural Georgia, who are receiving care for the most part through local health departments or places where there's a fee-for-service kind of scenario. And surprisingly at the very top of the list, we found three things. One was the provider's inability to accept

their life experience as being valid and that they felt as though they were being talked down to and that they were being minimized. So in other words, what they brought into the healthcare experience with them was their history of being African American and their history of being African American in rural Georgia, and also an experience around managing diabetes within the context of their family. And when they began to talk on those experiences, in that therapeutic environment, they felt as though that experience was being minimized and it was not being heard.

The second thing was that for the most part, their diabetes education came from members of their family or someone that they knew who had been living with diabetes. And there was this disconnect between whether or not the information they were told from family members or persons that they knew were living with diabetes and what the provider was saying. And so in other words, because the providers were not able to establish a level of trust, they were not going to necessarily abandon the information that they had received about diabetes from a loved one, a family member or someone that they knew had diabetes.

And the other issue was the amount time they spent in the waiting room before they actually went in to see the provider, they felt that if they had to sit and wait for long periods of time, that that sort of suggested then that they were not valued as important individuals. And that typically they had experienced that when they were in a fee-for-service or a local health clinic where they did not have to generate money to make payment for that, because they were in, for example, a financial bind, they could not make payment, that they somehow were seen and viewed differently. And that was carried into the provider/patient relationship experience. OK?

Let me end by sharing with a couple of the recommendations that I think are most important relevant to what I just shared with you today. And I am going back to the article entitled "Cultural Sensitivity: Definition, Application, etc., etc.". I'm looking at page 924. And on page 924 there are several recommendations that are listed here. And again, these recommendations were generated and shared with members of the American Diabetes Association who has been very proactive in making





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sure that this topic remains a topic of paramount concern for their providers. But there are a couple of recommendations that I think are really, really important, that I want to highlight. You all have them there for your reading. And I'm looking at the right-hand column. I'm going to start with the third recommendation from the very bottom.

First, practice active listening, which may help identify what is meaningful to people, very, very important. The second one from the bottom is replace deficit-based problem solving, problem weakness based philosophies and intervention planning with those that focus on individuals' and communities' historical strengths, skills and natural and human resources. And then finally, strategize and implement principles of participatory action research, in other words, that collaborative care model which advocates active involvement of populations affected in all aspects of planning programs. And I have talked a lot and I guess, Tricia, I can entertain any questions that folks may have.

QUESTION AND ANSWER

Operator

Thank you. The question-and-answer session will begin at this time. If you are using a speakerphone, please pick up the handset before pressing any numbers. Should you have a question, please press star one on your push-button telephone. If you wish to withdraw your question, please press star two. Your questions will be taken in the order they are received. Please stand by for your first question. Thank you. Our first question comes from Sandra Cummings. Please state your question.

Sandra Cummings

Hi, you mentioned that you talked about a systematic review by Susan someone on community programs. And I wonder if you can point me to where that's published and what Susan's last name is, please. Thank you.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Oh, sure can. That publication was written by Susan Norris. She is the lead author here and I am searching here. There are a couple things you can do. You can go to the CDC website and go to the Division of Diabetes Translation and all the publications that enter the CDC office have generated in the Division of Diabetes Translation, you can obtain them from the website. But I'm going to give you the name of the – it's Susan Norris and the name of the systematic review is called 'Increasing Diabetes Self-Management, Education and Community Settings'. And it was published in the Journal of Preventive Medicine 2002, Vol. 220, Supp. 4, pages 39 to 66. And what I can also do is to get that information to Tricia and she can send it out to everyone. Is that possible Tricia?

Tisha Crews Keller

Yes, that's fine.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

OK. Very good.

Sandra Cummings

Thank you.

Operator

Thank you. Ladies and gentlemen, as a reminder, should you have a question, please press star one at this time.





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Trina Thompson

Dr. Jack?

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yes.

Trina Thompson

Hi, this is Trina Thompson. I'm at the Tallahassee office. Thank you so much. This is – I have an anthropology background and I really have to say thank you for the wonderful medical anthropological perspective. And I was just curious as to how much anthropology background you do have? And then I have a question regarding the rural, older Georgians, with whom you conducted the focus groups, did you ever return to their providers and tell them a little bit about, you know, you're not listening to them, you're not doing active listening, is there anything that we could do to modify that so that these people can increase – you could find out you could increase their compliance. Did you ever return to those providers?

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

OK. First question was my background in anthropology, I don't have formal training in anthropology but I must say to you that over the years of being in public health and looking at where we are in addressing the burden of diabetes among particularly African Americans, I just simply got frustrated using the methodologies, approaches and strategies that I was trained in. And I recognize that in order to really get at understanding why groups of individuals who are given information about how to effectively manage their diabetes, for example, were simply not adhering to quote/unquote these recommendations. And so it just forced me to reach

out for a deeper understanding. And in order to obtain that deeper understanding, one has to step outside of their discipline and look at other areas where they have been able to successfully get that information. And then with that information, what I'm hoping to do in our work, is to integrate it in our work so that our interventions are more culturally appropriate and they have more sustainability. So that's the answer for the first question.

And the second question is did we go back to providers and provide that information to them. And the answer is no. We are hoping to do – now that we've done the focus groups, we use the focus groups to basically help us fine tune what that heuristic model – there's a publication out around the heuristic model to help us to identify some of these important processes that operate at the individual, the family level, that go beyond the person's internal stuff, the hemoglobin A1C, etc., etc. And we can then – that's a good suggestion. We can do that now that we are starting to implement the larger longitudinal studies that, with our findings, we can go back into these settings in rural counties in Georgia and share this information with providers. And then also, not just share the information about our observations but give them some strategies and some tips on how to better communicate with their patients. Good suggestion.

Operator

Thank you. Our next question comes from Andrea Williams. Please state your question.

Andrea Williams

Hi, Dr. Jack. I wanted to – looking at the outline where you had as item C, racism, what it is and what it isn't, I wanted a little bit more information to be touched on about the subtleties of racism that you have down there in that, I'm taking, for an example, how you said sometimes patients perceived from that small town in Georgia that you were talking about, that having to be made to wait a long time in the waiting areas before they saw their health provider





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that they didn't feel comfortable with that and that that distorted the time that they had together. What types of things can people do in those types – can professionals do in those types of situations to help ease that, to smooth that out?

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Right, I think one of the problems is lack of communication or lack to really – let me just put this out here, is – remember, early in my talk, I talked about that there are these paradigms that the provider has a body of knowledge that he or she is trained to use and to impart on the patient. And that's just the orientation. That's just sort of like how people are wired. And then the patient comes in with their life experience, as well as their experience in a healthcare environment where they received care before, or a family member has received care before. And they bring that history into the clinical setting with them. Is that both realities are really important, really central. And then just figuring out ways to encourage the provider to sort of let go some of the power and also let go of a notion that the patient's experience, whether real or not, in their own mind, should not be considered.

And in the case, in this example that I gave you about the counties in rural Georgia, what just sort of stuck out in my mind was, if you know for example you're not getting the kind of compliance around diabetes management that you would like, it suggests to me that there is now opportunity to do something different and to explore what that is. And I mentioned earlier, on an individual level, that all of us have to explore our shortcomings around interacting and working with different ethnic groups. So it may need asking some different questions of our patients around what that is about or finding someone as an agent of change to find those questions out.

And I've been really, really excited to see that emerging in the literature or a client-based systems who are using focus groups to find out a little bit more around what patients want from their provider, what makes them feel comfortable about being and interacting with their provider or they're asking

questions of patients who had higher compliance around diabetes self-management, what makes for that. And one of the things that surfaces is the patient/provider relationship. And there's a number of things you can look at that can sort of quantify what makes for a good patient/provider relationship, one of which is a sense of not feeling that you are nobody when you're in the presence of the provider, that what you say [unintelligible], also when your appointment is at one o'clock that you're seen at one o'clock.

And it's not very difficult to really grasp. When we think about, think about it from another perspective because sometimes when you say racism from the perspective of receiving care, why is that important. OK, let's wear another hat. If we say that customer satisfaction is very, very important, no one likes to wait for long periods of time. But if you are in an ethnic group that that typically is the experience or you've seen in not be the experience of other ethnic groups, then you may internalize it and make it one that is one about who you are in terms of your surface characteristics, your skin color, as well as where you sit in society relative to other people who look like you, then those issues become very, very prominent. And opening up to that information, the provider opening up to getting that information and then deciding to be proactive, to do something about it, is where the intervention lies. And it's a tough thing for some providers to do because they feel s though that's where they are, that's not what they've been trained to do, that's not what they're there for. They're there to provide care and it's up to the patient to actually get it or not get it.

But fortunately we're seeing more cases where the clinical environment is beginning to step out and embrace the whole need of respecting and understanding what is value to the patient before they come into the medical experience, i.e., making sure if they're on the schedule to be seen at one, then not seen at 1:45, somewhere close around one, that that is important. And that is something that cannot be ignored. I hope I answered your question.

Andrea Williams





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Yes, you did. Thank you so much.

Operator

Thank you. Our next question comes from Audrey Dorsett. Please state your question.

Audrey Dorsett

Dr. Jack, when you listed the -- mentioned the five areas, you think the five questions that we should ask the patient, there was one at the bottom, you said actually the summary, goal of the clinician should be to remain something ally. I missed out on that word.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Oh, therapeutic ally.

Audrey Dorsett

Thank you.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

... remain a therapeutic ally. Because again, my opinion [unintelligible] if the patient leaves without adhering or coming close to what the two agreed upon when they left, they're coming back and they're not going to be in the same state of health, they're probably worse, if they are not made to feel that you are the therapeutic ally that -- and listen, I -- I have certainly been in the setting where I've heard patients suggest how they propose to take care of diabetes and the inside, being that I come from a family that has a tremendous burden of diabetes, I'm from Baton Rouge, Louisiana/New Orleans. And so you know we eat down there. And so with all that being said, I

have heard in my family, as well as been in clinical environments, I've heard what people propose on a personal level that they would like to do to manage their diabetes and we know intuitively and intellectually, it's not the most appropriate thing for them to manage diabetes. But somehow keeping a straight face and negotiating around that is important because, and I know -- I hope I'm not taking up too much time, I know you asked what the word was that you missed, but I think this is important.

Audrey Dorsett

That's all right.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

-- is to make sure that the effort is to establish the trust and the connection and not on trying to refuse individuals knowledge around what they're proposing to be the right thing in terms of how they're suggesting they're going to take care of their diabetes. Because to do that cuts off all levels of trust and they're ability to hear the next word that you're going to say. So it's like being a therapeutic ally suggests that you're going to maybe sometimes not necessarily shoot down everything that the patient suggests at that moment. Over time maybe as the relationship gets better, you can begin to come around and address some of the other issues. But being a therapeutic ally, making sure that when the patient leaves that they have a sense that they were a part of the decision making, which is different from the traditional care model, more of a collaborative care approach.

Audrey Dorsett

Thank you.

Operator





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Ladies and gentlemen, as a final reminder, should you have a question, please press star one at this time. Our next question comes from Katherine [unintelligible]. Please state your question.

Katherine

My name is Katherine [unintelligible] Nigeria, I just from Nigeria, Africa.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

OK.

Katherine

I watched my dad died of diabetes and I have an elder brother-in-law that is suffering from diabetes.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

Yes.

Katherine

Now the question I want to ask is I'm working on diabetes awareness program in Nigeria.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

OK.

Katherine

Do you have any information on how I can get some [unintelligible] information from the United States? Is there anything like [unintelligible] in Nigeria?

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

Uh huh (affirmative).

Katherine

And somewhere else in Africa. [unintelligible] give me a guide on how to go about it and how to touch the people.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

Oh, sure, we can do that. Let me give you now my email address. Do you have a pen?

Katherine

Yeah.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention

OK. It's ljack@cdc.gov.

Katherine

Say that again.

Dr. Leonard Jack - Senior Behavioral Scientist - Center for Disease Control and Prevention





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OK. It's ljack@cdc.gov.

Katherine

OK.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

All right?

Katherine

Yeah.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Be glad to help you.

Katherine

Thank you. And one other thing I was going to say is
back home in Africa –

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yes.

Katherine

-- though we try to treat diabetes with managing the
food program.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yes.

Katherine

There are a lot of people also associated with
superstitious belief.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Sure.

Katherine

Because sometimes you're losing weight and you're
suffering from diabetes and somebody comes to tell
you that is witchcraft or that you're being punished
for some sins you've committed.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yes.

Katherine

[unintelligible] the patient lose hope and is really not
taking medication, is not even trying to eat.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yes.





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Katherine

Like well, if I'm being punished for a sin I've committed, then I have to die.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Right.

Katherine

Now, I need to know how to handle such people [unintelligible] to me and communicates with them so that he can have hope, that he can treat it and get well again.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yeah, I've had that question posed to me before. And a couple things. One is if there are other individuals who share these similar perspective to that, that there is this orientation that is a sense of fatalism, that something that they did in their past is the reason for the disease. If there is opportunity to point out individuals who felt the same way and had the same perspective, that those individuals when they took care of their diabetes would see the relationship between better self care, be it lifestyle, be it making changes in their nutrition and their diet, if they were able to see better outcomes, could be used as an example to those individuals who feel as though they can't improve because of something they did in their past.

And the other thing I've read too is that there is an opportunity here for another intervention and that is not medically oriented. And that if there are individuals in the community that are believed to be spiritual healers, individuals that are believed to have

gifts that they discern and help the individual to sort of process and work through this sense of guilt around maybe there was something they did in the past that I have seen in some cultures that those two paradigms, those two worlds are brought together where there is the holistic spiritual world, where there – in certain cultures, very clear usage of those – I don't know how to describe, those techniques or principles in those worlds that are combined with the use of traditional medicine. And sometimes again, that may or may not work, but just trying to look outside of just you as the health provider or someone as the health provider thinking that they can solely convince the individual to change their behavior or their thoughts, when in fact that other issue has to be addressed. And that may need to be addressed outside of the clinical environment.

Tisha Crews Keller

Thank you. We have one more question.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

OK.

Sandy Brown

My name is Sandy Brown. The question I have is in dealing with people with diabetes, some of them are on the pills and some are on the insulin shots, but I find that I'm having a problem with the ones that are on the pills because of the side effects that have been announced on television, that are in the journals, that they pick up when they were at the doctor's office, how you go about addressing that issue and letting them know that this is something they have to have.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention





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OK. Now, explain the side effects, Sandy.

Sandy Brown

As far as –

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

You said the patients are –

Sandy Brown

Say like impotence or weight gain.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

OK. Wow, that's a heavy one. That's the last question?

Tisha Crews Keller

So far.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Wow, that's a heavy one. Let me – oh, that's a real heavy one. Let me – because – let me start with the impotence one. This is a big one. We are – in our family intervention research project that we have in rural Georgia, we are looking at men and women, which for the first time, is being done. We don't see a lot in the literature around how men make healthcare decisions or who is helping them to make those healthcare decisions and/or if it's a significant other, what is the burden that is placed on the

significant other in order to keep the man healthy. OK, that's another topic. OK, Tricia, bring me back for that one. We also have to add a module, we have diabetes education module, we have like 12 of them. We had to add a module that talked about impotence because what was happening was, for example, in focus groups, men may or may not talk about impotence in the focus groups but will pull someone to the side and it just kept coming up and kept coming up. And so we figured we needed to create a safe place to have that discussion. And that is a real, real tough one because without taking the pill or the insulin, you know we have other complications that result that are connected to diabetes, but when patients, particularly from – especially from the male's perspective, the whole issue of masculinity being attached to one's ability to perform sexually and so sexual dysfunction being attached to masculinity and not being able to perform, brings on a whole other set of issues about self-worth, ability to maintain relationships, etc., etc. Yeah, that is – Sandra, I – that's a deep one. That is a very, very deep one. Because ultimately there has to be some acceptance around the loss of one very important aspect of being male, all right, and also resolving the issue that without intervention for diabetes, it leads to another set of issues. And I want to bring to your attention – excellent question because coming out in November in Diabetes Spectrum is a special issue dedicated solely to men and diabetes.

Tisha Crews Keller

Is there any –

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

There is an article in there that is written by Leandrus LeBerg [sp], myself, Apophia [sp], Fuma [sp] here at CDC and Ed Gray [sp], that will talk about illness narratives of black men and how they have interpreted diabetes and what you'll find in that article is their concerns around the inability to have sexual relationships, this whole issue of impotence. And what that means to them and how that has sort of





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manifest out in their lives of having connectiveness with a significant other and their ability to feel whole as men and what does that mean. I don't have a strong answer, but that is really a heavy one, because it essentially boils down helping men to accept that, if alternatives or interventions could be put in place to deal with the impotence as well as maintaining what is necessary for tight glucose control to minimize macro and micro complications to diabetes, if that can be achieved, then great. In some cases, they are not.

Sandy Brown

What about say male support groups in the African American community? How realistic do you think that is?

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

Yeah, I think that – I haven't heard of very many being tried. I don't think it's a bad idea. The issues would be one, finding a safe place for it to occur. Two, finding the right person to facilitate it, because in this instance, when you're going to talk about these kinds of issues, it is still going to be just as important to have someone that they can sort of self-identify with. I would think an individual who's been living with diabetes, who is a male, who has somehow men able to come to grips and acceptance around diabetes as a male would be important. But then there's some other things that would play out over time, they would burn out. And finding out ways of sort of keeping the group going without sort of using an individual who's been living with diabetes as a focal person to kind of keep the group going, because it's really taxing regardless if you have diabetes or not. That could be an alternative. I also see that there is perhaps an opportunity to involve the family in ways that have not been done before.

For example, very quickly, when we look at living with diabetes from a family perspective, we find that families that understand the disease or families who

are open being flexible helping the individual manage their diabetes, for example, they're not nagging him all the time about diabetes, families who can handle chronic stress independent of diabetes do better, families who can handle chronic diseases, i.e., diabetes, could help the individual deal with diabetes better. So I think that having the family involved is also another place for an intervention. So I think they're probably going to require multiple levels of intervention, perhaps occurring simultaneously in some cases. But this one is a real tough one.

Tisha Crews Keller

Dr. Jack, this is Tisha. We're going to have to close now. But thank you so much. I want to thank everyone for participating in today's teleconference. Please don't forget to mail us back the completed CEU forms and sign-in sheets to me. Fax number is 850-414-6625. Thank you and enjoy the rest of your day. Thank you, Dr. Jack.

Dr. Leonard Jack - Senior Behavioral Scientist -
Center for Disease Control and Prevention

All right.

Operator

Ladies and gentlemen, this concludes our conference for today. Thank you all for participating and have a nice day. All parties may now disconnect.

END

