

National Diabetes Education Program
U.S. Ethnic Group Differences in Diabetes Self-Management,
Family Support and Social Change:
DAWN2 Study and Implications for Practice
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Joanne Gallivan, M.S., RDN — Director, National Diabetes Education Program (NDEP) — NIDDK

Good afternoon, everyone, and thank you for joining the National Diabetes Education Program’s webinar, “U.S. Ethnic Group Differences in Diabetes Self-Management, Family Support, and Social Change: DAWN2 Study and Implications for Practice.” I’m Joanne Gallivan. I’m Director of the National Diabetes Education Program at the National Institutes of Health. As a joint program with the National Institutes of Health and the Centers for Disease Control and Prevention, our mission is to reduce the burden of diabetes in the United States by facilitating adoption of proven strategies to prevent or delay the onset and progression of diabetes and its complications. I’m sure many of you know that we host a variety of webinars throughout the year to support all of you working to improve diabetes management outcomes and prevent or delay the onset of type 2 diabetes.

Just a couple of logistics before we begin the main presentation: You’re all on mute, so we cannot hear you. We will hold a Q&A session at the end of the presentation. If you’d like to ask a question any time during the presentation, using the questions box in the control panel. If we have any questions that we cannot get to in the webinar, we will ask the presenters to respond to your question after the webinar is completed. The webinar is being recorded; we will post the video recording and presentation slides on the NDEP webinar page in about the next three weeks and notify all of you when the files are available. You will receive an email from NDEP this afternoon that asks you to evaluate this webinar. Please give us your feedback because we really use it to plan future events. And lastly, if you would like to receive a certification of completion for participation in this webinar, please send an email to ndep@hagerssharp.com, and that URL is on your slide right now.

So let me quickly give you an intro to the presenters. We are very excited to have two guest speakers today. First is Dr. Mark Peyrot, who’s a professor of sociology at Loyola University of Maryland. His recent project is comprised of multiple funded studies including surveys of psychosocial and behavior outcomes and determinants among diabetes patients, their family members and health care providers, including the DAWN and DAWN2 studies about patient-reported outcomes in diabetes clinical trials and studies about the drivers, consequences and relationships among diabetes, depression and diabetes complications.

He has served as leadership roles at the American Diabetes Association and the American Association of Diabetes Educators. He was one of the developers of the NDE — National Diabetes Education Outcome Survey, the AADE7 Self-Care Behaviors, and the National Standards for Diabetes Self-Management Education, as well as the National Standards for Outcome Measurement of Diabetes Self-Management Education.

Next we will have Marty — Martha Funnell, who is an associate research scientist at the University of Michigan’s Medical School Department of Learning, Health Sciences Education, and an adjunct lecturer at the University of Michigan School of Nursing, Division of Acute, Critical and Long-Term Care Programs. Marty, as you well know, is a pioneer in the area of diabetes empowerment. She’s an internationally recognized leader in the field of diabetes self-management education and diabetes support.

Marty's also past chair of the National Diabetes Education Program, a former president of Health Care and Education at the American Association of Diabetes — I'm sorry, for the American Diabetes Association, and a current fellow of the American Association of Diabetes Educators. Her work in diabetes education has resulted in numerous awards, including the ADA's Outstanding Educator in Diabetes Award in 1999 and the Distinguished Service Award in 1998, and she most recently received a Lifetime Achievement Award from the American Association of Diabetes Educators this past year.

And again, I'm Joanne Gallivan. I've been the director of the NDEP at NIH and NIDDK office for almost 20 years. I'm a registered dietitian nutritionist and a member of the Academy of Nutrition and Dietetics, the Diabetes Care Practice Group and the American Dietetic Association.

So now, before we begin the presentation, I just did want to announce, in terms of disclosures, that Novo Nordisk supported the original DAWN and DAWN2 studies, and Mark Peyrot is compensated by Novo Nordisk as principal investigator for DAWN2. And now I will turn this over to Dr. Peyrot.

Mark Peyrot, Ph.D. — Professor of Sociology — Loyola University

Thanks, Joanne. I'm going to be speaking mostly, in this session, about the data from the DAWN2 Study and giving you an overview of that, and then I'm going to be turning things over to Marty Funnell, who will actually discuss the practice implications of the findings, what we might make them and how you might use them in your practice.

So first of all, I would point out that the long-term goals of DAWN2 Study were to not only identify unmet needs of people with diabetes, their family members and health care providers, but also to raise awareness of those amongst the people who can actually change the way diabetes is treated and managed and responded to in today's environment. So we've tried to — through events such as this — to increase the dialogue between all the stakeholders involved in diabetes care and support and — with the goal of helping to improve the lives of those who are affected by diabetes — and also to bring this international flavor to this, to increase international sharing of practices and how we can all learn from one another.

Each country had similar sample — so here we're showing just the U.S. part of the sample, but there are about 17, 16 other countries — and as you can see, what we're going to be focusing on here is the study of people with diabetes and the study of family members. For people with diabetes it's broken up by type 1, then type 2, including those type 2 diabetes who are treated either with non-insulin medications, insulin medications or not medicated with that kind of medication.

The other thing that makes the U.S. study unique is that we included a separate sample of minority participants in order to have adequate numbers to be able to compare ethnic groups and examine issues of ethnic disparities amongst the people with diabetes and their family members. So the three minorities that we'll be discussing today are African Americans, Hispanic Americans and Chinese Americans, and again, here we also have a mixture of type 1 and type 2 for people with diabetes.

We're going to be discussing three parts, and what we're going to do is break them up in the data presentation and then a discussion of implications. So the first part will be dealing with self-management among people with diabetes, the second part will be dealing with the social support of family members for people with diabetes around their diabetes, and the third one will be the assessment of need for change in social conditions that might affect people with diabetes.

So first, self-management amongst people with diabetes; here's an overview of the sample for those of you who are familiar with it. It is a sample, as you can see, where we have more white non-Hispanics than

we do the minority groups, but we still have a substantial number in each of the minorities — and, as you can also see, broken out by different types of diabetes.

For self-management we included, first of all, the measure of frequency, which is the number of days per week in which people with diabetes adhere to these five aspects of diabetes management. And then we also assess something relatively new, which is the interest in improving adherence, and that was reflected in either that they are currently doing something to improve their adherence or they have a desire to do so if they have the necessary support. We won't be talking about foot checks, but we will be — for improvement — but we will be dealing with the other main concepts of the regimen.

So this is the format that you're going to see for a number of tables where we have, in this case, self-management behaviors that are being rated in each row, and we have the scores of the ethnic groups as well as the overall score when you read across. To help you a little bit understand the tables, you can see, as you're looking at them, that a letter attached to a number indicates which group that particular group is different from. So for diet, 4.7 with a D is the fourth group over, which is the B, Chinese Americans differ from white non-Hispanics. If there is more than one letter, it means that group differs from more than one other group.

So let me go over the table and point out some findings to you. I'm not going to walk through every number, but trying to identify what seems to be the important patterns. First of all we see that adherence for the total sample was highest for medications, intermediate for diet, foot checks and self-monitoring of blood glucose, and lowest for exercise. When we put all the items together that are not medication — because medication questions were not asked of all subjects, only those who are taking medication — we can see that overall adherence was highest for African Americans, with Hispanics and Chinese intermediate and white non-Hispanics lower, again, in terms of number of days in which they adhered to the regimen.

Looking at ethnic group differences, we can see that white non-Hispanics exercise less than all other ethnic minorities. Chinese Americans adhere to diet more than white non-Hispanics, whereas African Americans check their feet more often than white non-Hispanics and Chinese Americans, while Chinese Americans check less than other groups. So there's a number of ethnic differences here that seem relevant to the patient population and to what we might want to do in dealing with those populations.

The next table shows us the desire or effort or interest to improve self-management behaviors for these four, and then again, combined with all the ones that are not medication, and as you can see, there are a number of findings here. Interest in improving adherence was significantly higher for diet and exercise than for medication and self-monitoring of blood glucose. Looking at the overall score for multiple items, we can see that Hispanic Americans and Chinese Americans scored higher, while African Americans and white non-Hispanics scored lower.

In terms of ethnic differences, Chinese Americans were most interested in improving adherence for medication, self-monitoring blood glucose and diet. White non-Hispanics were least interested in improving adherence for medication and exercise. And I should point out that none of the ethnic group differences for interest in improving were dependent on the corresponding levels of self-management. In other words, these don't simply reflect the differences in adherence, they reflect differences in the way these behaviors are perceived and interpreted by different ethnic groups.

So to summarize, we can say that self-management profiles differ across ethnic groups; no single ethnic group showed consistently higher or lower predisposition or success across all adherence domains. White

non-Hispanics reported the lowest and African Americans the highest level of overall adherence, whereas Hispanic Americans and Chinese Americans reported the highest level of desire or effort to improve these aspects of adherence.

And so now what I'd like to do is turn it over to Marty Funnell to discuss some of the implications of these findings. And Marty's phone will probably come on shortly.

Martha M. Funnell, M.S., RN, CDE, FADE — Associate Research Scientist of Learning Health Sciences, Michigan Medical School — University of Michigan

Thank you, Mark. I'm trying to get to the slides here; there we go. I appreciate it and thank you for being with us this afternoon. So just to summarize what Mark was telling us is that what these results suggested is that diabetes educators and other care providers should consider and look at ethnic group differences when we work with people who have diabetes in helping them think about how they're doing and what they feel most capable and aware of improving. But it's also important not to get stuck in stereotypes.

So what we need to do is think about what questions can we ask to determine the cultural influences that our patients' experience. So we need to ask — and a question that we've asked for years on our assessment that works quite well, because it allows the patient to think through this issue and give you their own answer — is, "Do you have any cultural or religious practices that influence how you care for your diabetes?" And that gives the patients an opportunity to give you their side of the story or tell you how those affect them and how their family traditions affect them as well.

We also need to think about medications, including traditional and natural remedies, that our patients are taking. In thinking about lifestyle, we also need to consider how we can ask questions that will help us learn more about our patient's lifestyle behaviors and how we can be helpful to them.

My favorite question, always, to start a conversation is just the simple — ask people what's the hardest for them, the biggest struggle for them in managing their diabetes. I have a lot of energy to fix things that are hard for me and so that gives me a place to begin to work with the patient as an educator. In thinking about more specifically addressing issues, then, about the area that's hardest for them, asking them how many times in the past week did they or did they not do certain things, depending on what they've told you.

And then the real critical part of that is not just the number, but why, and what got in the way, and in helping patients think about what would help them be more faithful, but always in a way that lets them know you care about them, not that you're criticizing them and their efforts. Patients often feel very criticized, particularly in the area of lifestyle, and you have to be careful not to get involved in that; it's usually not very productive.

There are a whole variety of strategies you can use to work with patients in terms of lifestyle. We could do a, you know, five-day workshop on this topic, but there are some key elements. I think one is by asking questions; that gives you the opportunity, then, to address those things that are very important to the patients and take advantage of the moments those create by giving very specific information that's of interest to the patients, as opposed to just a lecture on how your beta cells work or what is diabetes.

I think it's also critical to realize that we shouldn't spend a lot of effort trying to change patients to fit diabetes. We need to think about what is the plan for how patients care for themselves. If it doesn't work in the patient's life, then it just doesn't work, and the nice thing about diabetes these days is there's lots of

options. So we need to focus on how can we adapt the plan to fit the patient, rather than try and come up with ways to maneuver and manipulate patients to fit our plan for them.

We need to teach them how to make changes, including doing things like asking each patient at the end of every class or at the end of every visit to just come up with one thing they can do better to manage diabetes. Diabetes is often very overwhelming for a patient, and nobody can do 100 new things, but most of us could do one. And we also work to set self-directed — which means the patient comes up with the plan — I-SMART goals. And you all know what SMART goals are, but we talk about I's; so it needs to be important, which means that it's a problem that the patient has identified — not their spouse or their doctor — and that they're inspired to fix it because it's actually going to do something to make their lives better.

Even though medication was one of the more positive areas, as educators I think we tend to forget about addressing the medications, or as providers we sometimes just assume that our patients are taking their medication, and that clearly isn't true. So one of the ways to ask that is just — we need to find out, we need to ask the question. Simply asking, “What percent of the time in a typical week do you miss your medication?” — my patients have a hard time understanding percentages, so we just say, how many times out of the last week, how many times a day.

But, you know, finding out how often it happens really isn't the important thing; the important thing is why. And I think particularly we need to find out if paying for it is a problem for patients, but also are there times when they make a decision which they believe to be the right one — not to take their medicines, and choose not to — and maybe that isn't really the best decision? They're basing it on misinformation or no information. Helping them think through what gets in the way of taking their medication, and that reason leads then to a discussion of what would help them to be more faithful, in terms of taking their medication.

Again, we're asking questions. We want to give people information from a data perspective so that they have the facts, but we also — as patients — also want to hear about what experiences of other people like me. So providing both of those pieces of information can help patients make more informed decisions about moving on to additional medication; that's particularly the case when it turns to insulin. And we also need to think about cost and coverage.

We also need to think about how to help patients get more from self blood glucose monitoring. Simply checking your blood sugar every morning for three months and writing down the number is not very useful to the provider or to the patient, so helping people think about what are they learning from this information, by asking them to explain to you what they see when they look at their numbers, asking how they use it.

Some other thoughts are to help people think about doing paired testing so they can see the impact on blood sugars of their behaviors, their exercise or their meal planning, or to do this very focused testing for just two or three days prior to an appointment that really gives you a full picture of their blood sugar and how it's affected by food, exercise, stress, all of those things. So it gives the patient a much better — it kind of links their behavior with their numbers, which is very useful for patients in terms of their learning.

The other thing is to think about — we talk about A1C; we need to help patients understand what that number means in terms of working towards target, not as a way to say, “You're not doing enough,” not assuming that lifestyle is to blame for an elevated A1C, recognizing that there are lots of ways — lots of

things that influence this, including the progressive nature of diabetes and the need for additional medication.

So one of the nice things about DAWN2 was that it also included some family members of adults with diabetes, so Mark, maybe you can tell us more about that.

Mark Peyrot, Ph.D.

Yes, thank you Marty; I'd be happy to do that. Our next section of the webinar is going to deal with ethnic differences in the frequency and perceived helpfulness of behaviors performed by family members to support people with diabetes.

This is the overview of the sample here, and as you can see, we have each of the four ethnic groups that we've talked about, and we give you a little bit of information about the people in the sample. As you can see, approximately half the people are living with the person who has diabetes, who is their spouse, but there are a number of different relationships that include parents, those who are other relatives and so forth. About half of the people who have diabetes are women, and a little bit over two thirds of the family members reporting about support are women.

So we looked at a measure of diabetes support, which was developed for the DAWN2 Study, and we here give the seven items that we assessed. And they are meant to capture a broad range of behaviors that people may or may not feel be supportive, including — well, they're all listed here; I won't bother to read them for you. One of the more interesting things that we tried to do, I think, is to separate out talking to the patient about how they're doing into two different domains — that is, reporting when people with diabetes are getting well and reporting when the person with diabetes is doing poorly. And then we can assess those differently to see whether they're more or less common — the former being more like praise, the latter being more like criticism — and then see whether those are helpful.

So here is the main data for this part of the study. As you can see again, it shows the four ethnic groups across the top, with the overall on the far right column and each of the seven behaviors occupying a row. Again, using the same standards as we did in the last table, the same formatting, asterisks indicates whether there's a significant overall difference, and then each mean is compared to each of the other means with the letters indicating which ethnic groups each other ethnic group differs from.

So, we can look at the findings and see some general patterns. The first is that when all the ethnic groups were combined, support was most frequent for listening to the person with diabetes and assisting them. Reporting when the person with diabetes is doing well was more frequent than reporting when they were doing poorly. Looking across the board, in all of the items discussed, white non-Hispanics had lower scores for providing support than other ethnic groups, and for most of them, it's all three of the minority ethnic groups. Chinese Americans were most likely, in picking one out, one difference, amongst the minority ethnic groups in terms of telling whether patients were doing poorly.

Now moving to the next table, this is in reference to how helpful the family member felt that their supportive behaviors were. As you can see in the far right column, when we combined them, support was perceived as most helpful when listening to the person with diabetes and assisting them, following by when the PD — person with diabetes — is doing well and doing activities with them. Doing activities for the person with diabetes rather than with them and offering advice were perceived as more helpful than reporting when the person with diabetes is doing poorly, which was the lowest ranked item of all types.

Looking at ethnic differences, we see that with the exception of listening to the person with diabetes, white non-Hispanics were significantly less likely than other ethnic groups to have rated their support behaviors as helpful. Chinese Americans were significantly more likely to have rated several behaviors as helpful, and this is compared to other ethnic groups besides white non-Hispanics.

So, to summarize our findings, family members reported substantial performance of support behaviors. All were above the midpoint of the scale, so they're fairly frequent. Overall, a majority rated all behaviors as helpful, with one exception. That's that one item we talked about: reporting when the person with diabetes is doing poorly.

A factor that we can see in looking at the tables is that family members more frequently engaged in supportive behaviors that they view as helpful, and that listening to the person with diabetes was the behavior most often viewed as helpful. Compared with white non-Hispanics, the three ethnic minority groups were more likely to report performing support behaviors and to perceive them as helpful, with Chinese Americans reporting the highest level of support and perceived helpfulness.

And so I think that gives us an overview of the findings, and then Marty will tell us about the implications of these slides.

Martha M. Funnell, M.S., RN, CDE, FADE

Thank you. I think as you've seen, clearly support and family involvement is important across ethnicities, and there are differences in those across ethnicities and also in family member — in different family members. So in some families, support and caring are shown by being very uninvolved in diabetes until asked, and in other families, caring and support are shown by doing much of the day-to-day care. So we have to respect those differences and determine what they are.

I think it's easy to criticize family members, but we have to recognize that in earlier DAWN2 data that was published, people with — family members of people with diabetes experience diabetes as a fairly significant burden, and clearly — and they also experience diabetes distress because of their family member's diabetes. Obviously it's worse if they have more to do or there's more conflict with that person regarding "You should/I'm not going to" kinds of conversations.

We also know that there were things that we can do to make it easier and better for family members, both to reduce their level of distress and also help people to be more supportive, so it really helps the patient and helps the entire family to be more effective in managing diabetes. So clearly, then, they feel more capable or successful in helping their loved one, if they have support from others in their broader social network and if they've taken part in diabetes education.

What we saw in DAWN was that 78 percent of people with diabetes indicated that attending diabetes was helpful and across the others, in the non-Caucasian, non-Hispanic white population, the numbers are pretty consistent. However, there are differences in family members with those who are Hispanic or Chinese American indicated more — that it was more helpful to them, although overall, 70 percent reported that education was helpful. So we need to make sure that we're inviting patients to bring family members to education as we can accommodate them and include them. If we do that, then we need to make sure that they get information about their job, in terms of how we — how they can be helpful to their family member.

So we need to ask patients, because we know support is so important, is how has all of this affected you and your family? Who is providing support for you? Are there things you need more support in? And it

may be that — what do you think would be useful in terms of getting the support you need? Helping the patient think about the kinds of support that will help them give them the information they need to convey to their families so they can truly be supportive and not just — and there would be less conflict.

We need to talk to our patients about the importance of support, let them know that no one expects them to do this alone and that we know that people do better when they get the help that they need. But they need to ask for it and they need to let people know how they can be most helpful. You know, a lot of times we find patients who excuse their family members' criticism by thinking — by saying, "You know, they think they're being helpful to me."

But if it's not supportive to you, then it doesn't really matter — then it's not support, even when they mean well — so we need to help them think about how to have a conversation about that as well. Involving them in making the plan to reach the goals — those step-by-step action plans, the I-SMART goals — involving their family in that also helps them be more supportive and maybe get involved, and in doing some of those activities with the patient.

We also need to talk to the family members — not just ignore them or view them as sort of off to the side during the visit or during the education program — but asking them similar questions, letting them tell us what would be helpful for them to know, what they're struggling with in terms of providing the support and how we can help to encourage them and support them and make it easier for them. We need to let them know that they need to be honest about their feelings. If I'm worried that my family member is going to develop the complications of diabetes, that's frightening to me; it's going to affect my life as well as theirs.

So letting them know that they need to talk with their loved ones, using statements like, "I'm worried about you," or, "I'm scared for our future because," rather than just saying, "You never follow this diet," or, "Why aren't you doing what you're supposed to?" Keep in mind — for family members, they don't have to be the only person providing support. If it gets too much to them, and many of our family members are older, have other health conditions, are suffering from chronic conditions or even diabetes themselves, they don't have to do it alone. You know, encourage them or encourage the family member to reach out to others to be help for him.

So Mark, why don't you tell us a little bit about some of the social implications of diabetes that we learned from DAWN?

Mark Peyrot, Ph.D.

Okay, thanks Marty; I'd be happy to. So first of all, this — we're going to be looking at a number of needs for improvement. This is the way the questions were asked, both to the people with diabetes and their family members, and we identified eight areas. Five — the first five are common to both the PWD Survey and the Family Member Survey, and then the bottom three were asked of family members only. And as you can see, these include psychosocial kinds of things, such as acceptance of the person with diabetes, but also social-community conditions themselves that are more institutional, that perhaps could be influenced by social policy, whether they be national or local level.

So here again is the data that we talked about for the minority groups. Looking at the five things where we are comparing — we also have data for family members — again, this data is pretty straightforward. What it shows us is that the white non-Hispanics indicate significantly less need for improvement for all of the social conditions we discussed. On the other hand, looking at the minority groups, we find that although they're all different than the white non-Hispanics, there are no statistically significant

differences amongst them, so it seems to be more a matter of minority status than of pure culture in terms of the ethnic groups.

Here we also have the percentage of family members who are reporting this. As you can see, again there's a generally consistent pattern for the white non-Hispanics to score lower than all of the ethnic minority groups, especially for the ones that were asked — also of the people with diabetes — but we see a similar pattern when we look at these new ones in terms of public acceptance of people with diabetes — or diabetes itself I should say — prevention of diabetes — as opposed to merely early treatment and diagnosis — and good overall medical care for them.

So the patterns basically suggest that the white non-Hispanics are the lowest in reporting need for improvement, Chinese Americans are highest for having perceived need for improvement, and African Americans and Hispanic Americans are pretty consistently intermediate in terms of their perceived need for improvement.

Here we break it out, simply collapsing the ethnic groups so we can get a sense of what are the priorities in the sample as a whole, for both people with diabetes and family members. And there's a remarkable consistency between people with diabetes and family members, with there being just a couple of percentage points, at most, difference for four out of the five social conditions that they rated. And the only one where there's a meaningful difference is with the acceptance of the person with diabetes, with the people who have diabetes themselves, feeling a greater need for this.

Next we can look at overall need for improvement by collapsing across the items. So here, taking the five items that were common both to the people with diabetes and the family members so that the norms — the values — are comparable across those two types of respondents, we see again that the white non-Hispanics see lower need overall for improvement of any type for both family members and people with diabetes, whereas for the people with diabetes, the minority ethnic groups are quite similar to one another. For family members there are some differences, with Chinese American family members seeing the greatest need for improvement, more so than for African Americans and Hispanic Americans.

So to summarize, all family members and PWD reported substantial need in improvement for all social conditions; perceived levels of need were similar for people with diabetes and their family members; and for both family members and PWD, the three ethnic minority groups reported significantly more need for improvement than did white non-Hispanics.

So Marty, why don't you tell us your thoughts about this?

Martha M. Funnell, M.S., RN, CDE, FADE

Okay, thank you. Clearly we have a job to do as health professionals and educators and providers in the broader community to make sure that living with diabetes and the social network around our patients is supportive for them. In conclusion, these results, as you saw, showed that ethnicity, also, and culture shape the way people think about the social conditions surrounding diabetes. And we also need to think about the health disparities and — I'm getting an echo, I'm sorry; is everyone?

Unidentified Speaker

No.

Martha M. Funnell, M.S., RN, CDE, FADE

Okay, sorry — and the health disparities that influence how our patients experience diabetes on a day-to-day basis. As health professionals, we have a role to play and our patients also have a role to play.

In terms of our own efforts, we need to — a big message from DAWN2, one of the major messages from it, is the importance of advocacy and the role of the advocacy effort. The American Diabetes Association, the Academy of Nutrition Sciences, as well as the American Association of Diabetes Educators, all have very strong advocacy work in place that we can get involved with.

A very specific example is that AADE is encouraging educators to work with legislatures in encouraging that they support creating a diabetes action plan in every state. Often, there are lots of efforts that happen somewhat haphazardly in terms of advocacy. Somebody has a great idea or, you know, someone brings up an idea, and so little pieces get put together, but by creating an action plan it gives you a framework to make sure that things are being done systematically and effectively.

We need to make sure that our patients get the referrals they need, including for self-management support and behavioral and mental health, emotional health resources as well. We need to address barriers that limit the access to these services, particularly in communities that are more affected by diabetes, but yet often underserved. We need to ensure and advocate and provide information to our patients about financial and other resources and keep up with what's going on in our communities that we can refer our patients to.

We also need to help people with diabetes get involved. Clearly they are the most powerful voices. When you go to legislators, they really want to hear from people who are affected, their family members — they want to hear their stories. They have much more impact than my talking about one of my patient's stories.

I think one of the things that's happened in recent years, and what we see in our own patients, is there's become somewhat of a stigma about diabetes, that it's somewhat of a shame. And that had to do with some of the prevention efforts, which are certainly very important, but then the sort of downside of that was that it — diabetes became viewed as the patient's fault.

So we need to reassure patients that diabetes is not their fault, there's nothing to be ashamed of, and, you know, they're the people who need to speak up. They're the people who are most effective and should not feel ashamed of saying, "I have diabetes," to leaders, to those around them, to get involved and provide support for others and advocate on a social level.

One of the things that we do is to have peer-based programs, and there are more and more of those around the country. Patients sometimes say, "Well, you know I'm not the best patient, and so I'm not a good patient," and what the studies have shown is that people who have struggled are actually much more effective than those perfect patients who've got diabetes and you know, now, within a week, are riding their bicycle 50 miles a day and lost 200 pounds. Most people are not there, and they want to talk with people who have struggled, and they want to work together with people who have struggled but who can help them to feel more positive and more effective.

You need to be your own best advocate. If you feel that things are not where they should be, then get involved and take part, including participating in community and educational fund-raising and support events.

So that concludes this component of the presentation. Joanne, you're going to tell us now a little bit about the national survey that NDEP just conducted. Thank you.

Joanne Gallivan, M.S., RDN

I am. Thank you both, Marty and Mark, and before — as Marty said, before we open it up for questions, I just want to share with all of you just a few highlights from some of the data that we have collected from the NDEP National Diabetes Survey. We launched the first survey in 2006 really because of the lack of awareness of national data on diabetes-related knowledge, attitudes and behaviors among U.S. adults, as well as the lack of data on the management and control of diabetes by people with the disease.

We have conducted the survey periodically, about every two to three years, since 2006 to provide NDEP with information on how we can focus our program strategies and also give us indications of the program's reach and effectiveness. While asking the same questions at two- to three-year intervals provided invaluable trend data, after we completed the 2011 survey, we concluded that the survey really needed to include new questions to better elicit information on intent to act and actions taken with respect to diabetes management and prevention.

Additional and targeted questions to capture progress toward behavior change, such as a person's intent to change, the steps they may take in preparation and changes they've made and the length of time they had sustained these changes were added to the 2014 survey. These questions focused on persons at risk for diabetes' perceived risk for developing the disease, as well as overall diabetes prevention and management behaviors, including confidence levels and management activities.

So in 2014 we fielded the survey. We sampled U.S. adults ages 35 and over, we surveyed 25 respondents and we oversampled for African Americans and Hispanics. And again, I just want to share with you just a few of the highlights. First of all, only 7 percent of participants reported regularly seeing a diabetes educator. This finding is very consistent with the data that was reported in the ADA, AADE and Academy of Nutrition and Dietetics joint position statement on diabetes self-management education and support. So this data point is pretty dismal.

More than half are not really confident in the following self-management behaviors: monitoring blood sugar, exercising or following a healthy diet. About two thirds of participants were not confident at all about what to do if they have hyperglycemia, and more than half did not feel confident about what to do if they have hypoglycemia.

And something that we continue to find is about one fourth of respondents reported not knowing about the link between diabetes and cardiovascular disease. We know that awareness about this link is getting better, but still some participants are still out there that don't really understand the link about the — between diabetes and CVD and diabetes and what they can do to prevent themselves from getting cardiovascular disease.

We will have more data from the Diabetes Survey that we plan to share once we public — we hope to have a publication on all the different findings from the survey, and we'll share the complete findings with all of our partners.

Remember, there are lots of related resources from the NDEP on patient education and clinical practice tools that you can use in your practice. You can see some of the resources on this current slide, and please, please go — please use these resources as much as you can and let us know how you're using these resources, because we always love to hear how our partners are using the resources; your feedback is really, really important to us.

So now we want to go to audience questions. If you haven't done so, please type it into the questions panel on your GoToWebinar screen, and Stephanie, I'll let you take us through the questions.

Stephanie Corkett — Senior Account Executive — Hager Sharp

Sure. Our first question is, when we see significant differences between white non-Hispanics and other ethnic groups on areas needing improvement, do we know how socioeconomic status or educational levels come into play here?

Joanne Gallivan, M.S., RDN

I think that's a question for Mark.

Martha M. Funnell, M.S., RN, CDE, FAADE

Mark, I believe that was a data question.

Mark Peyrot, Ph.D.

Yes, thank you. When we look at the data that was presented here, we are not adjusting for ethnic — excuse me, for educational or socioeconomic differences, it's simply looking at ethnic groups as a whole. We do know that these kinds of things may matter, and this is something — it's certainly worthwhile. We could speculate about it, but I don't really have unique results to report to you at this time.

Joanne Gallivan, M.S., RDN

The next question, Stephanie?

Stephanie Corkett

Yes, next question; this is also a data question for Dr. Peyrot. Was there any difference in effectiveness in the education program within age groups?

Mark Peyrot, Ph.D.

I would really have to dig down and look deeply at that, because in order for us to assess age, we have to un-confound it with all the other factors that it's associated with. So it's not a simple analysis just looking at age, since we know that people with type 2, for example, tend to be older, people who are — their type 2 diabetes is more advanced, older, et cetera, et cetera. So again, right off the top of my head I can't give that to you, but it is certainly something that we have the data to look at, and it is worthwhile, I think, especially when you perform those sorts of adjustments to make sure we're having an apples-to-apples comparison.

Stephanie Corkett

Thank you. Another question for Dr. Peyrot: I noticed the sample didn't include information from American Indians; will this population be included in the next study?

Mark Peyrot, Ph.D.

Oh, we would certainly love to be able to do that. I will point out that as with anything there — any study — there are limitations in terms of what it's possible to do. This is definitely an important minority that certainly needs a better understanding. I will also point out that trying to look at Asian Americans, we're getting a look at one group and that the Chinese Americans are not necessarily representative of all different Asian Americans. So yes, we would love to do this in more depth. There were not enough American Indians in the core sample for us to be able to address them, and so in order to do that, we're going to have to have an auxiliary study that, again, expands our sample for that ethnic group.

Stephanie Corkett

Thank you. The next question is for Marty. Stanford's Diabetes Self-Management Program seems to fulfill the needs of people with diabetes. What do you think of this program?

Martha M. Funnell, M.S., RN, CDE, FADE

I think that's certainly one approach, and it certainly has strong data. There are a variety of other programs, and I think what the data has clearly shown, in terms of education, is there's no one best program. I think the programs that are effective use many of the same elements that are present in that program that include a patient-centered approach, peer involvement. So I think we have to look at strategies rather than trying to pick a program and plunk it into our system. Sometimes that works, sometimes it doesn't.

The other thing I want to point out though about the first question that went to Mark is that I think the prevailing wisdom was always that folks in various ethnic groups tended to do worse than non-Hispanic whites, and I think what this study showed is actually that's not true, with the exception of diabetes-related stress. And so we need to think about assessing patients across groups and also ridding ourselves of some of the stereotypes that we suggest, which we assume that certain people are going to do better or worse, and really pay attention to that one person sitting in front of us and their families and their needs.

Mark Peyrot, Ph.D.

Indeed, Marty. I would not only support that but note that in the tables that we were presenting today, when we looked at a single ethnic group and compare it to others, we might say, "Well, members of this ethnic group score higher or lower than another ethnic group," but that doesn't mean that everyone in that ethnic group is high or low on that domain. So it is, as you said, still important to focus on one person at a time rather than trying to characterize each individual in a group by overall group average.

Stephanie Corkett

Thank you both. The next question is also for Marty. One viewer says she finds that the cultural questions just did fall flat and people don't know what she means by asking, "Do you have any cultural or religious practices that influence how you care for your diabetes?" Are there any other thoughts or ways to phrase this question?

Martha M. Funnell, M.S., RN, CDE, FADE

I guess I haven't have that experience, and I get interesting answers. A lot of times people just say no. I think another way to ask it is about family traditions or family patterns. You can even — if you understand or you're from a similar ethnic background — and you can't assume that, you know, that just because you are, you know what their lives are like — you can even ask about things that you've heard from other patients in that ethnic group. For example, does your family get together for a big dinner every Saturday or Sunday? Are there certain foods that are important to you from a cultural perspective?

So if that very broad question doesn't get you anywhere, asking more specific questions can give the patient a little bit better — they may not know how to think about it. I think in terms of religious practices, fasting is one thing that comes to mind which occurs in every religion, pretty much, that I've encountered, so again, ask — going from that more general question, if you don't get much from it, to more specific questions that you've learned in your experience or other patients have told you, or just kind of helping them think through it in a more specific way.

Stephanie Corkett

Thank you. The next question is for Joanne. Are there any NDEP resources that are tailored for specific ethnic groups that have been discussed today?

Joanne Gallivan, M.S., RDN

We have lots and lots of resources that are tailored for different specific ethnic groups. We have materials for Hispanic/Latinos, Asian American/Pacific Islanders — we have materials in up to 17 different languages for Asian Americans and Pacific Islanders — we have materials that are tailored for American Indians and for African Americans. And all of those materials were tailored with the help of our work groups from those representing those specific audiences.

So they helped us tailor those. And we also pretested those materials with members of the different ethnic groups to make sure they resonated well with them, and they could understand them, and they spoke to them and included you know, usual customs like Marty was just talking about. So if you go to the NDEP website and look on — by language or by ethnicity, you'll see all the different resources that we have.

Stephanie Corkett

Thank you. And then we had one final question that came in also for you, Joanne. How can we order these materials?

Joanne Gallivan, M.S., RDN

You can go to the NDEP website, you can go to www.ndep.nih.gov. All the materials are available online for you to download them, so please feel free to download our materials and copy them and distribute them. You don't need our permission to do so because everything is in the public domain.

You can also order certain materials from our Inquiry Center as well. There's a phone number when you go — if you look on that last slide, there's a phone number you can call to either order materials, but please, please go to the website and download all of the materials from NIDDK. We have materials on diabetes prevention and control, and we also have a lot of related materials on obesity, kidney disease and different digestive diseases. So you can go to the niddk.nih.gov website as well.

Stephanie Corkett

Thank you, and that concludes our questions.

Joanne Gallivan, M.S., RDN

Well thank you very much, everybody. Thank you so much to Marty and Mark for leading a great discussion and for answering all those questions. We also thank all of you for joining us. Again, to learn more about NDEP and our resources, as I just mentioned, go to www.ndep.nih.gov, or you can call the phone number that's on the screen.

We also very much appreciate your feedback. We will send you an evaluation that we ask that you fill it out and return to us, because we really, really appreciate your feedback. If you have any ideas for future webinars, please include those as well.

And if you'd like a certificate of completion for any CEs that you would like to obtain, you can send an email to ndep@hagerssharp.com; again, that's on your screen.

So that concludes our webinar today. Again, thank you to our speakers, and thank you to all of you for participating. Have a great afternoon!