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WHEN IT ALL GETS TO BE TOO MUCH: ADDRESSING DIABETES DISTRESS IN AFRICAN AMERICANS

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Diabetes is a serious, common, and at times, overwhelming disease that disproportionately affects ethnic minority populations. According to the Centers for Disease Control and Prevention (CDC), about 29 million people in the United States have diabetes, and African Americans are almost twice as likely to have diabetes as non-Hispanic whites.

People with diabetes are susceptible to developing diabetes distress, which is emotional pain that people with diabetes may struggle with as they attempt to manage a chronic condition such as diabetes on a daily basis. When left unchecked, diabetes distress can lead to poor self-management and can directly affect their health. Though there is limited research on diabetes distress in African Americans, it is well documented that diabetes complications including distress disproportionately are seen within this group.

This article describes common knowledge of how diabetes distress can impact African Americans with diabetes and purport to introduce diabetes educators to a tool such as storytelling to help deal with emotional health in this patient population.

Diabetes-Related Distress

Diabetes-related distress refers to the worries, stresses, and fears that often come with a chronic life-threatening illness (Fisher et al 2008). It is a normal and expected reaction and is not considered a clinical disorder. This is not to be confused with depression, which differs from diabetes distress due to its persistent and consistent presence over a timeframe of at least 2 weeks or more and a mood disorder that results in a loss of interest in daily activities that were once considered pleasurable (National Institute of Mental Health 2011).

When people with diabetes experience distress, they may feel overwhelmed by the day-to-day challenges of the disease, and their motivation for self-care can become low, which may in turn influence their eating patterns, physical activity levels, or everyday activities needed to manage their diabetes. It can also lead to social isolation and harmful coping behaviors, such as tobacco use, eating disorders, and drug or alcohol abuse (Cacioppo & Hawkey 2003; Lloyd, Smith, & Weinger 2005).

Age (being younger), gender (being female), education (low educational attainment), and health status (having diabetes complications and comorbid conditions) have all been identified as risk factors for diabetes distress (Fisher et al 2008). In addition, disproportionate exposure to social risk factors for health among ethnic minorities (eg, stress, discrimination, and poverty), cultural influences, and having comorbid conditions can all affect an individual's experience with diabetes. For instance, for African Americans, perceived stress, daily hassles, perceived seriousness of diabetes, as well as experiencing more than 1 chronic illness have been found to be associated with diabetes distress (Spencer et al 2006). Moreover, having less support from providers and dissatisfaction with health care they receive were also associated with high levels of emotional distress.

Studies by Hausmann, Ren, and Sevick (2010) and Spencer et al (2006) found that African Americans may experience higher levels of distress than whites and this distress may interfere with their daily life activities and diabetes management. Given the assertion that African Americans with diabetes are at higher risk for diabetes-related distress, health care providers need to explore emotional health as part of the clinical visit as this can help improve the patient's ability to cope with the everyday stressors associated with managing diabetes, help improve coping skills, and decrease risk of complications due to poor self-care.

Although some level of distress is part of the disease process and is to be expected, addressing what is distressful can lead to better diabetes outcomes for patients. It is worth noting that both the AADE7 Self-Care Behaviors framework and the American Diabetes Association Standards of Care agree and recommend need for routine assessment and care for psychosocial issues (American Association of Diabetes Educators [AADE] 2015; American Diabetes Association 2015).

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Understanding and Addressing Diabetes Distress in African Americans

While all people with diabetes are vulnerable to diabetes-related distress, addressing this issue in this population can be challenging. Often a patient's decision to seek help is influenced by cultural perceptions of appropriate ways to cope with daily stress and the stigma associated with seeking help. This outlook may prove to be a barrier to open communication about situations and issues the patient is encountering when talking to the provider or diabetes educator.

When looking at cultural nuances, African American women often feel they are expected to project a “superwoman” image and demonstrate strength in the midst of societal and personal challenges (Woods-Giscombe 2010). In African American communities, experiencing depression and being “stressed out” are seen as weakness. Individuals may believe that personal problems will work themselves out without the need to acknowledge the stressful event and without having to “air one's dirty laundry” to others. Historical trauma and the victimization of African Americans are added layers that have fostered a sense of distrust of the health care system (Ward & Heidrich 2009).

It is therefore important to develop new strategies to address diabetes-related stress in these patients. One such strategy that may help overcome some of the cultural barriers to addressing emotional issues within African Americans is the use of storytelling. Stories can ignite the participant's interest by creating vivid mental images that encourage thinking and aid understanding and recall. Storytelling places information in a context that makes it meaningful and memorable, which can help people reframe issues and consider alternative choices.

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An African American patient who is uncomfortable talking about his or her personal issues can instead talk about the person in the story. This can make it easier to probe into personal worries and challenges without violating cultural norms or the patient's privacy. When the diabetes educator and patient do not share the same cultural background, stories can also help build understanding and trust. As the diabetes educator listens to how the patient responds to the story, he or she can learn about the cultural or life factors that influence how the patient copes with life's challenges.

Role of the Diabetes Educator

In working with African American patients with diabetes, diabetes educators can play a pivotal role in helping their patients identify and address emotionally challenging issues that can influence diabetes self-care. Diabetes educators can address emotional distress by teaching problem solving and healthy coping skills and providing a supportive environment for patients to talk about the challenges of managing their diabetes.

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The AADE7 Self-Care Behaviors framework has a section that addresses healthy coping and can be useful for encouraging patients to talk about their stressors, worries, and fears and for teaching skills to better cope with the emotional ups and downs of living with diabetes. The National Diabetes Education Program (NDEP) has also developed the *New Beginnings Toolkit*, specifically targeting the African American population to address stress management, goal setting, communicating with health care providers and family members, emergency preparedness, and other skills needed to make positive changes in diabetes management and improve coping skills.

Guide to Incorporating Storytelling Into Diabetes Education

There are many approaches to incorporating stories into diabetes education. They can be used to introduce a topic, illustrate a problem, demonstrate a skill, or provide encouragement. Stories can be shared using video, audio programs, or print materials, and educators can become skilled at telling stories with practice. In addition, some people with diabetes and their family members may be willing to share their personal stories for use in educational programs. In order to be effective, the stories should be engaging, relevant, and relatable to patients.

Stories with characters who share the same background or life experiences as patients can have great impact in helping them open up about their own experiences, while stories with characters of different backgrounds and experiences can help patients think about the influence of their own culture and how it affects their behavior. To be effective, it is advisable to choose short stories that are related to the objectives being addressed during that visit.

Patients should be given time to process the story and talk about what takeaway message they derived from it. It is important to ask open-ended questions about the story and explore how the patient may have made similar or different choices than the characters. Avoid telling patients what the story is supposed to mean, as different people might have different interpretations based on what is important to them at the time. One should not be afraid to use stories where the characters make mistakes, as these kinds of stories provide valuable learning opportunities for patients.

NDEP's *New Beginnings: A Discussion Guide for Living Well With Diabetes* uses stories to guide discussions. It includes 8 modules that address a variety of psychosocial issues such as healthy coping, stress management, problem solving, and effective communication. This guide may be used as part of a comprehensive diabetes selfmanagement education program or adapted for a single patient, a patient and their family, or a group of patients such as support groups.

New Beginnings includes different stories and scenarios of African American families living with diabetes that both the educator and patient may find helpful in starting a dialogue in a safe and nonjudgmental manner. Conversely, it is important to be aware that one person's approach to managing these challenges may differ from another person's and can be influenced by environmental exposures, cultural experience, gender, age, socioeconomic stressors, or other factors. Diabetes educators must be sensitive to these differences in order to provide culturally competent guidance and emotional support.

Other storytelling resources through the "Reach, Teach, and Heal" series from the Centers for Disease Control and Prevention (CDC) are also available to provide guidance on ways to incorporate storytelling in diabetes education. It includes stories that are appropriate for use in clinical and community settings and can be found at <http://www.cdc.gov/diabetes/projects/ndwp/education/talking-circles.htm>.

Improving Cross-Cultural Communication

In order to be an effective educator, AADE recommends that educators learn about the culture and medical practices of their patients with diabetes and how this might affect behavior. Diabetes educators need to consider techniques that will improve cross-cultural communication with their patients, hence increasing the patient-provider experience.

For example, it may be helpful to work with peer educators or community health workers who have a similar background or life experience as patients to help them feel more comfortable opening up about emotional issues. According to Jones et al (2008), family involvement in diabetes education and management may also be a great source of support

for many African American patients. Some African Americans may rely on religious or spiritual support as a coping mechanism for managing their disease, and diabetes educators should encourage these patients to seek spiritual guidance as a way to manage distress. Skills that support patient empowerment, along with active listening and plain language communication, can help create an atmosphere that supports effective cross-cultural communication.

Although we do not fully understand emotional distress in people with diabetes, we do know from psychosocial research that ways in which people respond to distress can be affected by cultural factors. According to the National Institutes of Health (NIH), cultural competency is crucial to reducing health disparity and for improving access to quality health care in a respectful manner that addresses diverse needs of patients while taking into account the cultural and linguistic needs of the patient. Therefore, it is important to understand cultural nuances to provide effective care to these patients.

Important elements of cultural competency that educators should be mindful of include personal identification (eg, how the patient will like to be called—an African American may not feel comfortable or feel offended being called by first name if they don't have a personal relationship with the person), language, thoughts, communications, customs, beliefs, and values that are pertinent to meeting needs of the patient. Educators must be careful to avoid stereotyping patients while remaining culturally sensitive.

The key to becoming culturally competent is learning to negotiate cultural divides and communicating with patients in ways that increase understanding of how culture may or may not play a role in how that individual manages their diabetes. Therefore, educators should continue to find ways to connect to their patients and address any barriers that can hinder success.

Pearls of Wisdom

Some other action steps educators can take are:

- Checking in with patients regularly. Ask how they are coping with their diabetes.
- Being alert for signs of depression but not losing sight of the everyday stressors that can interfere with self-care.
- Reminding patients that stress is normal. It's how we cope with it that makes a difference.
- Encouraging patients to talk with their family, friends, or spiritual leaders for support.
- Reminding patients that it is OK to ask for help and take time for themselves.
- Working with community-based organizations such as faith communities, worksites, and community centers to start peer-led diabetes support groups.

Conclusion

Diabetes is a complex disease that can be challenging for people to manage on a day-to-day basis. Culture often plays a role in the way people respond to diabetes-related distress. Therefore, it is important that educators continuously find ways to connect with their patients and address any barriers in a timely and culturally sensitive manner.

Culturally sensitive diabetes educators can play a significant role in helping patients address emotional distress that can otherwise negatively affect self-care and diabetes-related health outcomes. Frameworks such as AADE7 Self-Care Behaviors and culturally tailored tools like *New Beginnings* that use storytelling should be implemented to address barriers to self-care and effective diabetes self-management. Storytelling can be a useful strategy for improving self-efficacy, outcome expectations, risk perceptions, and problem solving, especially in this vulnerable population. In addition, actively listening to the patients' stories can help build trust and understanding while enhancing communication.

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RESOURCES TO SUPPORT EMOTIONAL HEALTH

- *New Beginnings Discussion Guide*, a guide for leading group discussions about the emotional side of living with diabetes. <http://www.cdc.gov/diabetes/ndep/new-beginnings.htm>
- Diabetes Health Sense, a resource for finding diabetes education materials including tools for healthy coping. <http://ndep.nih.gov/resources/diabetes-healthsense/index.aspx>
- American Diabetes Association Standards of Care 2015 includes recommendations for including psychosocial assessment and care in diabetes self-management education. http://professional.diabetes.org/admin/UserFiles/0%20-%20Sean/Documents/January%20Supplement%20Combined_Final.pdf
- Diabetes Distress (American Diabetes Association), an article about diabetes-related distress. <http://www.diabetes.org/living-with-diabetes/complications/mental-health/diabetes-distress.html>