

African American psychologist living with type 2 diabetes

Introduction

I'm an African American psychologist living with type 2 diabetes. I have to admit that from the announcement of my diagnosis I was a difficult patient. With all of my education, I protested, I rebelled, I denied what was happening to me. I was angry at the medical profession. I was angry at my body. I was angry at the hand fate had dealt me. Looking back, I see now that I was grieving. It was essential that I accepted the fact that my lifestyle would never be the same because my body was in distress. I had to acknowledge the changes I needed to make were also the very changes my medical providers had been suggesting for years (e.g. work out a little more, try to cut out fast food, eat a healthier diet). That came in time, but what I needed most was a setting where I could vent, where I could be heard, where my anger would be validated as normal, where I could get beyond the shock and start partnering with my medical providers. Instead, I was told to make an appointment for a six-month check up to test my blood levels again and to use the time in between to see if I could manage my diabetes without medication.

This is the problem all patients face when given a life-changing diagnosis. It is especially troublesome for African American patients, especially males, and those who face limited access to healthcare or have fewer financial resources. Physical and attitudinal barriers exist that can prevent or discourage an African American patient from seeking an early diagnosis, pursuing follow-up treatment, or adequately participating in and complying with treatment plans. These barriers range from lack of transportation to a medical facility, no appointments that dovetail with work schedules, lack of consistent childcare, long waits for an appointment or during appointment times, and time commitment issues.

Coupled with financial considerations, insurance limitations, and co-pays, these barriers can discourage a patient from seeking routine medical care that could provide early diagnosis. Physical and financial barriers result in patients coming to a physician only when it is an emergency.¹ Psychological and attitudinal barriers, however, may be the hardest to overcome. These stem from a deep distrust of the healthcare system. The medical profession, like modern psychology, is built upon an orientation provided by the dominant culture (specifically, white, European American descent, middle-class, male, heterosexual, Christian, English-speaking, and able-bodied).²⁻⁵ Compounding this are differences in communication style and language (esp. idioms of distress), deep divides between a culture's ethics and that of the majority culture, and traditional taboos about involving outsiders. This can lead to stereotyping, stigma, cultural/racial paranoia, and the lack of others of their culture in medical professions, as well as misdiagnosis because the healthcare professional doesn't understand the patient's culture.⁶

Culturally-sensitive healthcare providers must also deal with the aftermath of historical oppression of certain groups and modern day poverty.^{3,7} In addition, monocultural (those of the majority culture) diagnostic assessment tools and treatment modalities not only can perpetuate barriers to treatment but may also contribute to

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misdiagnosis and poor treatment outcomes, especially when dealing with psychological aspects of treatment.⁴ Some patients also confront condescension and uncivil behavior in institutional settings from healthcare providers thus contributing to more distrust.⁸

Historical oppression of African Americans has resulted in a general mistrust of the healthcare establishment. This was deeply rooted in generational slavery and racism throughout the twentieth century and is still present today overtly and covertly. Harriet A Washington, in her book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*,⁹ reveals a long history of medical experimentation on African Americans from plantation owners who sold or hired out slaves to doctors for experiments to medical schools and carnival shows that bought African American cadavers from whites for study and display.

This kind of dehumanizing practice continued into WWII when the U.S. military experimented on African American airmen of the 332 Fighter Group, a segregated unit that had distinguished itself through service during the war.¹⁰ Two hundred airmen with syphilis were refused treatment, even though penicillin had been a proven drug to treat the disease, in order to study how syphilis progressed in the human body.^{9,11}

Mustard gas and radiation experiments were also performed on African American military personnel, as well as biological weapons experiments targeting this population.¹² African American prison inmates were also used in various forms of medical tests and drug trials. In addition, sterilization and genetic experiments were performed on men and women. Based on faulty neurological and behavioral theory and bias, some physicians performed radical brain surgeries on African American children because they were hyperactive.⁹ All of these procedures over the centuries were done without the consent of the people who were the focus of this experimentation. These incidents have created a pervasive, generational mistrust of the medical profession that manifests further into concerns about misdiagnosis and wrong treatment options (Hackett, 2014; Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006). Further, this serves as an unconscious reason to delay medical treatment, not to seek it at all, or not comply with treatment regimens (Jacobs, Rolle, Ferrans,

Whitaker, & Warnecke, 2006). These personal and institutional barriers can also contribute to added stress for patients with any diagnosis but especially those with life-changing ones.¹³

African American males, in particular, may not seek medical treatment immediately or at all due to John Henryism. This coping style, or resilience factor, is found in both men and women (Howard, Dryden, and Johnson, 1999; James, 1994; James et al., 1992; James et al., 1987; Uden and Elofsson, 2001), but seems to be more socially observed among males (James, 1994). The John Henry Hypothesis, developed by Sherman James (1994), is a stoic copying mechanism used to manage psychological stresses generated by life events that can include health issues such as diabetes and hypertension.¹⁴ This theory is based on the folk hero, John Henry, an African American farm worker who was so strong he was challenged to compete against a spike-driving machine to prove who was the fastest and strongest. John Henry won the completion but died immediately after from mental fatigue and physical exhaustion. Individuals who demonstrate this same stoic fortitude to plunge through life as if invincible are said to display John Henryism. Ironically, John Henryism can contribute to and intensify hypertension and other stress-related diseases.¹⁵

Equally important, patients who are given a life-changing diagnosis experience shock, disbelief, and grief across all ethnicities.^{16,17} They also display the same five stages of grief as Elisabeth Kubler-Ross¹⁸ identified in those who had lost loved ones. Those stages are denial, anger, bargaining, depression, and acceptance.^{18,19} None of these are necessarily negative stages but are coping mechanisms that help individuals pass through grief and mourning onto other adaptive ways to manage their lives. Newly diagnosed patients go through a transition, and they mourn the loss of a lifestyle with which they have become comfortable.

However, newly diagnosed patients, particularly those with diabetes, not only first face denial (“This can’t happen to me.”) but also fear.¹⁷ They fear how this will change their lives, how medical emergencies will impact their loved ones, and how to cope with the horrors of serious complications (amputations, blindness). Anger is directed at fate handing them this diagnosis or at themselves for not preventing the diagnosis or complying to treatment as expected. Anger most often targets the healthcare system for not being more available to discuss concerns and offer comfort. Bargaining is usually expressed as looking back and wishing the patients had taken better care of themselves or had an earlier diagnosis.¹⁷

Depression is a common byproduct of mourning and dealing with a serious illness. This often stems from feelings of helplessness about coping with a disease that often overwhelms their lives and from the loss of what they could eat or do before the diagnosis.¹⁷ Depression in African Americans with diabetes is very common and can also greatly influence patient self-management (Edge & Bonadonna, 2003). Unfortunately, African Americans with diabetes and co-morbid diabetes are less likely to follow treatment recommendations.¹⁶

Acceptance comes not as an end to mourning but more as a process to living with the disease. Patients begin to find ways to make small changes in their habits and in their lifestyles. However, none of this happens without education about the disease and support during the morning process.^{17,19}

All of these stages of grief I experienced as an African American who was newly diagnosed with diabetes. Even though I am in the healthcare profession myself, I sometimes felt ignored and

marginalized by my own doctors and my own personal history and attitudes. It is critical, then, for medical providers to understand their greatest tool at the onset in working with someone with a new diagnosis of diabetes is kindness. There are other much needed changes that must be made in treatment protocols that are not just adjunct therapies but also essential behaviors and understandings.

New Treatment protocols for African American patients with diabetes

I have personally heard healthcare personnel talk down to African American patients and rushed out of offices after being given a life changing diagnosis with only a pamphlet and a diet plan flyer in their hands. This does nothing to foster compliance nor trust in the medical profession. There are sound ways to help a patient deal with the shock of this diagnosis and help them understand the changes they must make. All of this will take time.

Creating Rapport

Extra time is difficult for many physicians in fast-paced clinics and hospitals where seeing as many patients as possible is the rule. But it is a crucial element in helping a newly diagnosed patient. Schedule a longer appointment time in order to answer questions the patient might have and help them initially weather the shock of diagnosis. Also, understand that it will take more than a few minutes for the patient to fully grasp how this diagnosis will impact their life. Simply saying, “I’m going to help you live with this,” will make an impact. After all, partnering with patients in their healthcare treatment will generate rapport, trust, and compliance. This is the first step.

All healthcare personnel must also realize that there is a need for a deeper understanding of those not within the majority culture, who especially may feel marginalized and disenfranchised, and work toward building a culturally-sensitive practice model. Healthcare workers should be aware of how their own place within the majority culture and their own assumptions about a patient’s culture can affect how they treat those patients. They need to understand that the patient’s experience is always colored by cultural difference. Therefore it is essential that healthcare providers offer culturally-sensitive and patient-specific interventions and treatment modalities.^{4,5,20} Having contextual knowledge of a patient’s life beyond demographics and lab results, including behaviors such as John Henryism, helps to provide an appropriate and specific treatment plan that the patient can follow with a realistic and positive outcome.

In my practice, I look at a patient’s general culture as well as family-specific traditions, beliefs, strengths, and coping strategies. The strength of these in individual cases may be revealed in the initial interview but may not appear until later when the patient’s trust has been extended and the patient relates personal narratives that include information about spirituality, religion, beliefs, dreams, and the use of traditional healers. These stories are often deeply revealing of the cultural world view the patient and the family share and help me avoid misdiagnosis due to cultural differences.^{21,22}

Language and code switching

When I do individual evaluations from networking referrals within my community, I usually involve a native-language interpreter because often these patients speak English poorly or not at all. A native speaker is better suited to nuances and idioms within the language than someone who has studied a foreign language, no matter how

skilled they are. This is especially true of languages such as Spanish or Chinese that have many different regional dialects. These nuances of language allow me to narrow my focus on what a patient's issues really are, just as I do with native English speakers who use familiar idioms.^{3,7,4} In addition, patients who deal with foreign-born doctors may experience cultural and language barriers. Having a nurse or physician's assistant who is familiar with common English present could assist creating better understanding with patients. My current practice is designed to be sensitive to the patient's culture, socio economic status, gender, education and sexual orientation. With this in mind, I focus on the individual and his/her place within the family per the Afrocentric practice model, which includes the central place of the family, traditional/cultural roots, religious ties, and cultural/familial strengths (strong achievement orientation, strong work ethic, flexible family roles, and strong kinship bonds).³

Often I use a technique called code switching as a tool during interactions with patients. Each culture has a specific code within its language that is beyond the use of idioms. For example, Asian patients will be very direct but also will use many pauses within communications. African American code is often rapid-fire and sprinkled with colorful, sometimes, offensive language.^{23,24} When I see a patient code switch, often it is an indication the patient is ready to "get real," meaning they are comfortable enough with me as a therapist and a person to get deeper into the issues they are dealing with. Though I may drop into the vernacular of a particular client's culture, I always maintain a clinical perspective.

Code switching is defined as the use of two or more linguistic styles in the same interaction.^{24,25} Research by Godley, et al.²⁶ has shown that even when individuals speak what may be called broken English, it is not a valid indicator of the patient's overall intelligence, but may indicate something else. Code switching allows me to show appreciation for the patient's method of communication and also expresses my willingness to be led by them during the therapeutic process. I do not place judgment or demand that the patient speak in a manner that is more comfortable for me as the therapist.²³ During the therapeutic process, code switching can serve as an indicator the patient is inviting the provider to join them in a style of communication that is more comfortable for them, and it also serves as a cue that the patient is ready to explore the topic deeper but needs to be able to express feelings around the topic in a more familiar way.²⁵

Though code switching may be a technique with which many in the healthcare profession are quite unfamiliar, regular spoken English is. As medical personnel explain to a patient that diabetes is manageable with or without medication by making subtle adjustments to their daily diet and routine, it must be done so in plain English. Traditionally, medical providers bombard the patient with A1C ranges and blood glucose levels and other technical medical jargon. This is sometimes too much information too fast. I value the fact that I went to school to learn how to translate large words and terms into a format that the least educated among us can understand. This is essential so that patients understand what they must do. But it should be done with tact and the utmost respect. While working at the Duke University Diet and Fitness Center years ago, I learned to understand that pushing overweight people to go cold turkey on their favorite foods was just setting them up for failure. I work with my African American patients to better understand how their traditional cultural diet is, in part, a major cause of their illness and how gradual changes can be made that will help. I also tell them they can eat grandma's fried chicken on Sunday but have a salad with it.

Being heard

Research has shown that when working with African American males, rapport is the first critical step in developing a helping relationship in a healthcare setting (Steckel, 2013). These men tend to initially agree to medical suggestions during the evaluation then immediately ignore them and rely on old maladaptive coping once they leave the office. One way to establish rapport with these patients and others is to engage in empathic listening⁴ and to provide an environment where the patient feels heard. This is done by reflective listening where healthcare providers repeat what they think they hear the patient report about feelings and their understanding of the medical instructions. This helps engage the patient in the process and to feel like an active participant in treatment goals and by evoking different ways of managing the patient's frustrations and make maintainable behavioral changes that support adapting to a healthier lifestyle of living with diabetes (Garvard & Clouse, 1993). These have been shown to improve outcomes and increase physical activity for patients with diabetes.⁸ African American patients often respond well to providers who are able to respond to them in the moment in ways that show compassion and understanding vs. condescension. African American patients also respond well to providers who not only educate them but also start off the process with them as a partner in the healing process (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006).

Respect

Another area for providers to consider when working with African American patients is the possibility of perceived micro-aggressions by the patient from the providers or their staff. Micro-aggressions are perceived slights that may have subtle racial overtones. The unfortunate thing about micro-aggressions is they are not stated and are only left to the discernment of the victim (Sue et al., 2007). African American patients may interpret being rushed at check in or not being greeted as kindly as the person before them in line as racial micro-aggressions when they are in a predominately white environment. These can lead to increased heart rate, which of course will concern the provider when doing checking vitals. Simply talking to the patient and smiling can help immediately. It has worked for me as a patient and reduces my blood pressure from the start of my appointments when it is rechecked at the end of the doctor's visit. Also, a sign of respect for African American men is to refer to them as "Mr." and use the word "sir." Avoid slipping too quickly into first name familiarity with these patients. Call them by their first names only when invited.

Support

Social support from family members and a good relationship with their providers play a significant role in African American patients, especially males, adhering to medical advice and following through on appointments and proper self-care. Also, for African American males, seeing the negative impact the disease has had on close relatives and family members is key and a great tool to motivate them to self-manage (Hawkins et al., 2015). African American male patient-provider relationships are critical, especially given the common reluctance to seek help due to social history and also the admission they need help. Rapport and a sense of respect and concern by the treating physician are critical for African American males (Hawkins et al., 2015). Hackett (2014) saw a critical need for more African American healthcare providers in order for this population to feel that they were being heard and treated by professionals who

had an understanding of the culture and generational distrust of the medical realm.

In order to encourage compliance, patients often need the support of their families and wider communities. This is especially important in African American and Hispanic households. Including the patient's wider family in office visits and encouraging connections with community elders, religious leaders, and healers, when warranted, can help support a patient in various ways. Many ethnic families are multigenerational, meaning there may be three generations living under one roof, and often participate in coparenting younger children.^{27–30} This not only can be another source of worry and stress, but it can also be an additional source of empowerment and support. These more traditional and alternative sources provide additional psychotherapeutic support for certain patients.^{3,22,31}

To increase compliance with African Americans, a great starting point is the patient's family and place of worship (Hankerson, Suite, & Bailey, 2015). Though today's medical model emphasizes confidentiality, bringing a patient's pastor or preacher into the treatment protocol has its challenges but can be done without breaching medical ethics. If a church home is central to an African American patient's life, perhaps it should become part of the treatment plan. In my experience, patient compliance increases immediately and dramatically because the patient feels supported by the larger community through prayer and other means. Support of family, church, and community is far better than sending a patient home to figure everything out alone.

Solid treatment information

Kahn et al.¹⁷ found that patients across cultures had little understanding of the causes of diabetes, usually resorting to misinformation passed around among their families and friends. It was essential that information about the disease and all treatment protocols are explained in simple English in as small or large portions the patient can understand.

For African American males, it is imperative that providers understand it is common for them to present for medical treatment once the symptoms of diabetes are severe (Hawkins et al., 2015). Diabetes is a disease that has several potential side effects if it is not managed properly (eye damage, organ damage, limb damage). The patient should be made aware of potentially negative medical side effects of diabetes during initial education about the disease to help the patient understand the significance of diabetes and also the individual's ability to control these potential negative outcomes. When possible, the patient's treatment should include an interdisciplinary treatment team that is in contact with one another so that each part of the patient's care is monitored and adjusted with the most accurate data available. For example, the patient's attendance with the nutritionist and missed appointments to the primary care physician are all data points that the patient's team can use to address with the patient when a concern presents itself or if the patient's A1C levels are not under control even after the proper patient supports have been put in place.

Conclusion

Dealing with African American patients with diabetes can be challenging. Culturally-sensitive healthcare providers can ensure greater treatment compliance through personal education about cultures that are not their own. Insights about culture-specific behaviors such as John Henryism help engage a patient where he or

she is at the moment and can provide doorways into approaching a difficult patient. Information about diabetes must be in a readable form (sometimes that means translated into another language) so the patient grasps the clear meaning of what the diagnosis and treatment plan is. This produces understanding and respect for doctor and patient. Most of all, healthcare providers must help patients deal with the shock and grief of this life-changing diagnosis. This begins in the physician's office and extends to every healthcare provider who is in contact with the patient. A referral to a therapist who deals in medical grief counseling may be necessary or the physician may suggest the patient speak with his or her priest or minister. Grief is grief, whatever the cause. Finally, kindness and patience are the best resources you have as a healthcare provider.

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Conflict of interest

The author declares that there is no conflict of interest.

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