

Assessing the cultural appropriateness of UPLIFT for African Americans with epilepsy: A community engaged approach

Josalin J. Hunter-Jones, MSW, MPH, CHES¹, April L. Nellum, MS², Elizabeth I. Olorundare, MBBS, MPH, FWACP², Candace C. McCloud, MPH², Matthew D. McCurdy, MPH², Robin E. McGee, MPH¹, Contessa M. Davis, MPH², Nancy J. Thompson, PhD¹ and Rakale C. Quarells, PhD²

¹ Emory University, Rollins School of Public Health, Department of Behavioral Sciences and Health Education, Atlanta, GA² and Morehouse School of Medicine, Department of Community Health and Preventive Medicine, Atlanta, GA

Corresponding Author: Josalin Hunter-Jones • 1518 Clifton Rd NE, Atlanta, GA., 30322 • 404-727-7043 • jjhunte@emory.edu

ABSTRACT

Background: In trials of Project UPLIFT, a distance-delivered, mindfulness-based cognitive therapy intervention, there was improvement in the mental health of people with epilepsy/seizure disorder. In these trials, however, African Americans have been few. Thus, as this program is disseminated, it is desirable to ensure that it is culturally appropriate for minority populations.

Methods: To determine the appropriateness of Project UPLIFT for African Americans, we engaged in three main research activities: 1) the formation and involvement of an epilepsy community advisory board; 2) qualitative interviews with healthcare providers who serve this community; and 3) focus groups with African American adults living with epilepsy or seizure disorder and main support persons of African American adults living with epilepsy or seizure disorder.

Results: The epilepsy community advisory board provided recommendations for the most appropriate language to use when engaging and recruiting the target population. Healthcare providers indicated that psychosocial concerns of African American persons living with epilepsy seemed to be different from those among patients of other racial groups. They indicated that Project UPLIFT might be useful for this group. Focus groups revealed experiences of living with and supporting someone with epilepsy and provided favorable feedback on the UPLIFT intervention.

Conclusions: Formative feedback indicates that Project UPLIFT may be useful for African Americans with epilepsy. These data will be used to guide a forthcoming randomized, controlled trial to assess the acceptability and feasibility of the intervention with this group.

Key Words: epilepsy, mindfulness-based cognitive therapy, depression, telephone, qualitative, community advisory board

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INTRODUCTION

Defined as “a condition of the brain causing seizures,” epilepsy affects more than 50 million people worldwide (de Boer, Mula, & Sander, 2008; WHO, 2016). More than 4 million U.S. adults have been told that they have epilepsy (Centers for Disease & Prevention, 2012). One in 26 Americans will develop epilepsy in their lifetime (Epilepsies, 2012). Despite advances in treatment and an increase in knowledge about epilepsy self-management (Epilepsies, 2012), there are, within this population, racial/ethnic disparities in health and healthcare.

More than 630,000 African Americans have been diagnosed with epilepsy and more than 370,000 have “active epilepsy,” defined as having a prior diagnosis, reporting at least one seizure in the past year, and/or currently taking medication to manage seizures (Centers for Disease & Prevention, 2012). Despite being less likely to have active epilepsy, at a rate of 5.2 per 1000 compared to 5.9 per 1000 among Caucasians, African Americans have a higher lifetime prevalence of epilepsy at a rate of 7.5 per 1000

compared to 5.9 per 1000 among Caucasians (Centers for Disease & Prevention, 2012).

African Americans tend to engage in 70% fewer specialty visits (such as medical visits to neurologists or epileptologists - doctors who specialize in diagnosing and treating the disorder) than Caucasians, are three times more likely to visit the emergency room for seizure emergencies and related injuries, and five times more likely than Caucasians to be hospitalized due to a seizure-related incident (Begley et al., 2009). In a study comparing medication adherence between Caucasians and African-Americans, researchers observed that African-Americans had significantly lower medication possession ratios for antiepileptic drugs than did Caucasians, indicating poorer adherence (Bautista, Graham, & Mukardamwala, 2011). Furthermore, African Americans are at increased risk for sudden, unexpected death in epilepsy, as compared to other racial groups (Zhuo et al., 2012).

Despite evidence that African Americans are disproportionately affected by epilepsy in health and

healthcare, little is known about psychosocial contributors to these disparities. Research targeting differences in epilepsy experiences have focused primarily on types of seizures and medically explained differences in epilepsy diagnoses; fewer studies have focused on psychosocial concerns related to the experience of being an African American living with the condition or on mediating mechanisms that might lead to such disparities. A study of predominately Caucasian adult epilepsy patients, quantifying perceived stigma in relation to demographic and psychosocial factors, found associations between stigma and the interactions of seizure worry and employment status, self-efficacy and social support, quality care, and age at seizure onset (Smith et al., 2009). For minorities with epilepsy, however, there are few studies that focus on stigma and related psychosocial concerns. One such study investigating barriers to healthcare, treatment options, and treatment adherence for African Americans noted that financial limitations, poor communication between epilepsy patients and providers, a lack of education about epilepsy in the African American community, and a lack of social support, particularly instrumental support, exacerbate the aforementioned disparities (Paschal, Ablah, Wetta-Hall, Molgaard, & Liow, 2005). The research described in this report explored and described experiences of the African American epilepsy community in an effort to adapt and evaluate the usefulness of an evidence-based mental health intervention for this population.

For people living with epilepsy, depression, with an overall prevalence of almost 1 in 4 (23.1%), is the most frequent psychiatric comorbidity (Fiest et al., 2013). Co-morbid mood disorders, such as depression, that remain unaddressed and untreated can affect medication options and are associated with a poorer quality of life (Keezer, Sisodiya, & Sander, 2016; Noe, Locke, & Sirven, 2011). A study on African American pediatric epilepsy patients demonstrated the need to screen them for undetected depressive symptoms (Roeder, Roeder, Asano, & Chugani, 2009). Although this research was focused on children and adolescents, considering the lack of research in this area for African American adults with epilepsy, these findings might have implications for this population as well.

Funded by the Centers for Disease Control and Prevention (CDC), Project UPLIFT (“Using Practice and Learning to Increase Favorable Thoughts,” hereafter referred to as “UPLIFT”) was designed as a distance-delivered program for managing depression (Thompson et al., 2010). The intervention was designed as a group intervention, delivered by phone or web; participants received UPLIFT materials to engage the intervention from home. For persons with epilepsy, home-based treatment for depression delivered remotely helps to overcome barriers such as transportation, physical access, and the lack of motivation to which depression often contributes. UPLIFT is a manualized intervention facilitated by a licensed mental health clinician and is typically co-facilitated by a person with epilepsy. The intervention incorporates education about depression, mindfulness, and cognitive-behavioral therapy. It also

teaches skills including thought-checking and meditational exercises and provides “on-your-own” practice assignments to complete between sessions. More information on intervention content and format can be found in previous articles on UPLIFT (Thompson et al., 2015; Thompson et al., 2010; Walker, Obolensky, Dini, & Thompson, 2010).

In a randomized, controlled crossover trial, UPLIFT was effective in reducing depressive symptoms in a sample (N=53) of Georgia residents with epilepsy and comorbid depression in the high-mild to severe range (Thompson et al., 2010). Another randomized, controlled crossover trial demonstrated that UPLIFT could prevent the onset of depression in people with epilepsy (Thompson et al., 2015). In both studies, knowledge (of depression) and skills (for mindfulness or cognitive-behavioral strategies) increased and depressive symptoms decreased in the intervention groups as compared to the treatment-as-usual waitlist groups (Thompson et al., 2010; Thompson et al., 2015).

Given the success of UPLIFT in preventing and treating depressive symptoms in diverse samples of persons with epilepsy and the observed health disparities in epilepsy among African Americans, it seemed likely that UPLIFT is a program from which African Americans might benefit. The CDC therefore funded a proposal targeting the adaptation of evidence-based epilepsy self-management programs for African Americans in Georgia, since this racial group is disparately affected by epilepsy/seizure disorder and represents at least a third of Georgia’s population (U.S. Census Bureau, 2015). This research is a collaborative effort between Morehouse School of Medicine and the Rollins School of Public Health at Emory University.

The data presented in this report are focused on the following research activities, presented in this sequential order in each section:

- 1) The formation and involvement of an epilepsy community advisory board (E-CAB);
- 2) Qualitative interviews with healthcare providers who serve African Americans with epilepsy; and
- 3) Focus groups of African Americans with epilepsy or seizure disorder and the main support persons of African Americans with epilepsy or seizure disorder.

METHODS

Establishing the Epilepsy Community Advisory Board (E-CAB)

Community advisory boards (CABs) are a recommended tool for involving communities in community-based participatory research aimed to reduce health-related disparities associated with chronic diseases (Newman et al., 2011). CABs provide a mechanism to facilitate the community-academic relationship and provide feedback between partnering groups (Israel, Checkoway, Schulz, & Zimmerman, 1994). Additionally, for research teams and communities, CABs increase ethical engagement; provide

protection for research participants and communities; promote cultural appropriateness of programs, mechanisms, and procedures; and ensure the comprehensive dissemination of research findings (Quinn, 2004; Strauss et al., 2001).

African Americans with epilepsy belong to two distinct groups, both of which are marginalized and stigmatized (Mays, Cochran, & Barnes, 2007; Thomas & Nair, 2011). Construction of the E-CAB was instrumental in ensuring that the research team understood the experiences, needs, and concerns of the target population; their friends, family, and support persons; and the medical professionals who provide care to this community. These perspectives were necessary in providing the research team with knowledge of how best to adapt UPLIFT.

Recruitment & Membership

To construct the E-CAB, the research team recruited individuals using a purposive methodology with the intention of selecting between seven and ten members. Inclusion criteria for potential E-CAB members included belonging to one of four participant groups identifying as (1) an African American person with epilepsy; (2) a main support person of an African American living with epilepsy or an individual who provides assistance in areas ranging from disease management to emotional support; (3) a healthcare professional serving African American epilepsy patients; and (4) an advocate for either African Americans as a community or people with epilepsy. The initial E-CAB consisted of seven community members: three persons with epilepsy; one support person; two healthcare professionals; and one community advocate.

Governance

By-laws were established to guide the community-academic partnership and to provide underlying procedures for governing the E-CAB. The by-laws outlined several aspects of governance, including the establishment of Chair and Vice Chair positions; the categories of participant membership as outlined in the previous section; methods for removing a member from the board; and the frequency of E-CAB meetings. Additionally, the research team developed a list of responsibilities for the E-CAB Chair and Vice Chair. Assigned duties included providing leadership to the research team in areas such as cultural appropriateness, community engagement, and communication; creation and maintenance of effective community and academic partnerships; attending meetings; and participating in community events and other study-related activities.

Healthcare Provider Interviews

Procedures

Healthcare providers (N=5) living in Georgia with experience in treating African Americans with epilepsy were interviewed to obtain their thoughts about the best ways to recruit this population. These providers were recruited mainly through snowball sampling methods via E-CAB members. In interviews of these providers about

recruitment strategies, they were asked their perspective on the experiences of African Americans with epilepsy.

Data Collection

All eligible individuals were invited to participate and were asked to provide informed consent. The study sample consisted of five diverse health care providers—a chiropractor, a nurse practitioner, a psychologist, a neurologist, and an epileptologist. Qualitative data were collected through in-depth interviews that took place between May and September of 2015. Each one-hour, semi-structured interview was conducted by two trained members of the study team who served as the main interviewer and assistant. The study instrument was an in-depth interview guide, which was used to obtain responses of participants to demographic questions and five subject areas, namely: 1) experiences of providers in delivering care to the target population; 2) experiences of stigma by their patients; 3) their perception of barriers to healthcare for their patients; 4) self-management needs specific to this population; and 5) channels for recruitment and dissemination of epilepsy self-management programs, including UPLIFT.

Data Analysis

Interview recordings were transcribed verbatim. Independent thematic analysis was conducted by two coders trained in qualitative research methods. Deductive analysis techniques were used to create themes from the interview guide. Each transcript was reviewed by both coders, and, for comparison, verbatim quotes were selected based on these themes. After the coders identified quotes from the transcripts, they met to compare and group quotes and to determine collectively if there was substantial support from the interview transcripts.

Focus Groups

Procedures

Two groups were targeted for participation in focus groups: African Americans with epilepsy and the main support persons for African Americans with epilepsy. Those with epilepsy were recruited to participate in focus groups if they identified as African American or Black; had been diagnosed with epilepsy or seizure disorder at least three months prior; and were Georgia residents, 18 years or older, English-speaking, mentally stable with no reported plans or intent for suicide, willing to attend a two-hour focus group, and willing to be audio-recorded during focus groups. Support persons qualified to participate in focus groups if the persons with epilepsy who they supported identified as African American or Black, were diagnosed at least three months prior, and were Georgia residents at least 18 years or older. The support person him/herself had to be English-speaking, mentally stable with no reported plans or intent for suicide, willing to attend a two-hour focus group, and willing to be audio-recorded during focus groups.

Participants for focus groups were recruited by disseminating flyers at the offices of member physicians within the Grady Health System Neurology Clinic and the

Emory Healthcare Neurology Clinic, as well as on the website of the Epilepsy Foundation of Georgia.

Data Collection

Individuals who screened eligible based on the inclusion/exclusion criteria were invited for focus group participation. Focus groups took place from September 2015 to January 2016. All eligible participants were asked to provide informed consent. One week prior to the scheduled focus group, each participant was mailed a packet containing UPLIFT materials for review. Data were collected from four focus groups with African Americans with epilepsy (N=22) and from two focus groups with main support persons of African Americans with epilepsy (N=13). For those with epilepsy, there was one face-to-face focus group and three focus groups conducted over the telephone. Telephone focus groups were open to each participant as an option if travel or participation in face-to-face focus groups was not convenient or easily accessible. Participants were invited to select their preference for focus group format. Although telephone focus groups limit the ability to read non-verbal behavior, they provide a viable alternative to face-to-face focus groups (Krueger & Casey, 2014). In particular, persons with epilepsy sometimes have difficulty accessing transportation due to state driving restrictions, seizure safety-related concerns when accessing alternative transportation, or the desire for anonymity regarding their epilepsy or seizure condition. Therefore, providing the option of participating in either face-to-face or telephone focus groups helped to eliminate the bias of enrolling only participants who were able and/or willing to attend focus groups in person. Face-to-face focus groups were held at Morehouse School of Medicine. Both face-to-face and telephone focus groups were facilitated by an African American and co-facilitated by an African American who supports a person with epilepsy. All focus groups lasted approximately two hours. Discussions included knowledge and perceptions of African Americans regarding epilepsy and epilepsy stigma along with epilepsy self-management behaviors. Time was taken to review activities from the UPLIFT intervention.

Data Analysis

After the focus groups were completed, audio-recordings were transcribed verbatim and checked for accuracy. Names and other identifying information were disguised. One transcript from each category was reviewed to develop a codebook. Upon drafting the codebook, the second transcript from each category was reviewed to ensure that the codebook was complete. Afterwards, two coders independently coded each transcript to determine if there were any discrepancies. A thematic analysis approach was used to identify the range and priority of prominent issues related to epilepsy, epilepsy stigma, and epilepsy self-management presented during the groups as well as thoughts and opinions regarding UPLIFT materials.

RESULTS

E-CAB

The E-CAB was instrumental in identifying the appropriate language and approach to soliciting participants for focus groups and provided feedback on UPLIFT activities. For example, E-CAB members recommended that we change the word “caregiver” to “support person” on study documents, indicating that, for some African Americans, this language insinuated that the person with epilepsy was unable to take care of him/herself, an implication that some were uncomfortable with. Those individuals seemed to be more comfortable with the language “support person,” as it implies that someone is assisting them to care for themselves, typically through providing instrumental support. This finding corroborates previous reports in which instrumental support, such as transportation to appointments or to pick up medication, is essential for African Americans living with epilepsy (Paschal et al., 2005). Additionally, E-CAB members suggested that, rather than limit language on study documents to reference those living with “epilepsy,” we should include “seizure disorder” to accommodate those who might not feel comfortable identifying their condition as “epilepsy” or who may have been diagnosed with a “seizure disorder” but may not be aware of or remember whether the diagnosis was epilepsy explicitly. Modifications to study documents were made in accordance with these suggestions. These suggestions will be utilized for future dissemination of epilepsy self-management programs targeting this population.

Healthcare Provider Interviews

Five healthcare provider interviews were conducted. During analysis of the data, several major and minor themes emerged. Providers presented some psychosocial concerns that they frequently encountered with African American epilepsy patients:

1. *Stigma*. Providers shared that many of their African American patients with epilepsy experienced stigma in their relationships, work places, and community. Furthermore, the perception of a few of these providers was that this stigma is the result of myths and misinformation that exist about epilepsy and mental health conditions, such as depression and anxiety in the African American community. One healthcare provider shared the following:

“Unfortunately, diseases of the mind, depression, anxiety, bipolar disorder, schizophrenia – it’s culturally not accepted that well...I think there is slightly more of a stigma in accepting psychiatric etiology in the African American population than other populations.”

2. *Mental health concerns, including anxiety and depression*. From the perspective of the providers, African American patients were seen as less vocal about their experiences of panic, anxiety, and depression as were patients of other races. Some of the providers attributed this to a different perception of self and/or different ways of

handling the attendant stress of having a chronic condition. For example,

“...Most of them are not having panic attacks. I guess maybe some anxiety, but it is different – I would say not as depressed I think... Caucasians appear more critical, more judgmental to themselves...The African American community comes up in a different way, so they're more light about all of it, not beating themselves up, but it comes out in a different way...”

Others, however, saw it as being due to the cultural unacceptability of these mental health conditions in the African American community:

“...A lot of times I try...to direct them [African American patients with epilepsy] to get special mental services like a psychiatrist or psychologist, but that is also another challenge because a lot of them see it...like they're crazy, so that it's difficult for them to kind of go to this type of treatment even though I try to convince them that that's just part of – of their disease, that we have to treat it too.”

3. *Productivity.* Compared with their feelings about their mental health status, African American patients with epilepsy seemed more concerned about being able to maintain their productivity and ensure the quality of life for themselves and their dependents. Discussions between providers and patients therefore revolved mainly around ways of coping with their altered quality of life.

“[Patients with epilepsy ask:] How do I balance that? How do I be productive? How do I do what I want to do? And how do I be okay that I can't do what I used to do...how do I still be happy...and not be angry and resentful?”

4. *Access to quality care and resources.* Providers indicated that quality care for patients with epilepsy was limited, and that several barriers to accessing care still exist. These barriers include finances, transportation, misinformation about treatment options, and mistrust of the healthcare system. For example,

“...there's a lot of mental health issues and the sad part is. . . They [specific healthcare system] will not see patients with Medicaid, so basically these people have to go elsewhere and a lot of other counties don't support them.”

“I would say if they're [on] Medicaid, they get transportation except rural Georgia because rural Georgia, they – you know, Medicaid van's supposed to get you, but some of them won't pick them up because it's too far away ... One way or another, they have trouble. Like I have one guy, now that we've moved here, you know, the old place used to be on the bus line. This isn't. He goes I had to take three different buses and it took me

2½ hours to get here, and he lived in downtown Atlanta.”

“I would say that in general African American patients are less apt to seek medical care just because of the history, you know, that we have as a race concerning clinical trials, like the Tuskegee Study...so I think that that's one thing. Simply just fear, mistrust of the medical system in general.”

“Well, the economical challenge is the biggest one, I would say...that makes it difficult for them sometimes to adhere to the treatment even if they want to...in general they are very receptive of the instructions that I give them and very respectful of the plan and we discussing it together...they might not agree with certain treatments that might be beneficial for them just because they consider that it's – it's difficult to accept that kind of treatment, like the surgery...”

5. *Family support.* Healthcare providers were of the opinion that, in general, the informal support systems for their African American patients appeared to be more robust compared to those of their Caucasian patients. As one of the providers observed:

“African Americans...they're often in here with their whole family and Caucasians are by themselves...I'm talking grandmother, momma, everybody. They all come in and tell me everything, like everybody's here and the Caucasians like have an Uber ride or whatever...”

However, the burden of providing this level of support often took a toll on these support persons, negatively affecting their mental and physical health and well-being:

“They [support persons] still have a lot of stress and tension...in particular the mothers—and this seems to happen with everybody but it – it seems harder I think for them to take care of themselves maybe a little bit... the grandmother or the mother...because they're taking care of so much—depending on how functional this person is—but their stress management isn't great, so there's not necessarily anxiety, panic attacks, but they're certainly not exercising. They're not walking.”

Additionally, the support persons themselves need more support, particularly in the area of provision of factual information regarding epilepsy/seizure disorder.

“Well, I guess I'll say certainly more actual information, you know, about epilepsy to kind of help them kind of understand, you know, within the African American community in general there are a lot of myths related to different diseases...so to get more factual information so that they could be of assistance to the person from that perspective. I

think that would be really key...To have an understanding of a disease so that if by chance a person has a seizure, you know...they would have an idea of what's happening, number one, and what would be the appropriate actions to take."

In addition to being asked to share their experiences in providing care to African American patients with epilepsy, the health care providers were briefly introduced to UPLIFT and asked to share their opinions on the intervention, in particular, how this population of patients would respond to UPLIFT. All five providers stated that their African American patients with epilepsy would benefit from participating in UPLIFT. However, they also voiced concerns about utilizing this as a telephone-based or distance-delivered intervention and suggested that the researchers consider incorporating an in-person component to cater to desires of patients to have contact and support on a more personal level.

"I'm a big fan of people dealing with people and not having barriers of communication versus them being at home alone. I – I don't know, but it'd be better than probably nothing if there is some type of support coaching and knew how to, you know, therapists on board teaching the group skills... So to me it would be more effective to be the people...in the group setting...but it would be harder to do in a telephone setting."

"I think telephone, it's – it's a good start. I think the – the better effort is more in person. I think that helps more, but I – I think the response would be – I mean, well, it's better than nothing...I don't think it's the optimal.. I think with epilepsy patients in general and certain diseases, I think more one-on-one at least at one time and then follow up over the phone works very well..."

"... I mean, phone would probably work, you know? ... I think a lot of them if they could talk to other patients, they would be willing to do so because they don't get out..."

Focus Groups

Sample

All focus groups for persons with epilepsy (N=22) consisted mostly of women between the ages of 20 and 83 years, with 43 years being the average age. The most frequently reported characteristics of persons with epilepsy participating in focus groups were never being married, did not graduate high school, and currently unable to work. As for focus groups with support persons (N=13), most participants were between the ages of 45 and 66 years, with the average age being 57 years. Most support persons reported attending some college or were currently retired.

Persons with Epilepsy Focus Group Themes

1. *Lack of knowledge about epilepsy, and stigma.* Participants believed that people with epilepsy were viewed

in an unfavorable way because many people did not understand the condition clearly or had not been provided accurate information about the condition. Many of the participants in the focus groups believed that, because many people are not properly educated on the condition, there were still myths, misconceptions, fear, discrimination, and stigma surrounding epilepsy:

"I'm oftentimes having to explain to people that it's not a disease. It's a disorder. You know you're not going to catch it. People are even still saying it's a demon. I mean there's a whole lot of ignorance and just lack of education around the disorder. "

"I think it's a very negative stigma with it. I think it's just like everything else the fear of the unknown. People just don't know what it is exactly or how to explain it. They just don't know..."

2. *Mental health concerns, including anxiety and depression.* Participants felt a common frustration because their condition led to various mood changes. Having epilepsy affected participants physically, mentally, and emotionally.

"...I feel like just the frustration of just the day-to-day living, not knowing what's going to happen is pretty like depressing. It takes effort to keep yourself uplifted and remaining positive because it's real easy to get down on yourself."

"I always think about being something else, having something else, not having this condition. Where would I be? Who would I be? If this happen, where will I go? I'm always second guessing and guessing myself. I'm not listening to nobody around me. It's just all about up here. I mean past situation, present situation, future situation. It's just constantly rolling on and on and on."

3. *Lack of control.* Many participants felt that the unpredictable nature of the seizures resulted in a feeling of not being in control. In addition, they indicated that lack of control was a challenge for them because it brings on limitations in their lives, such as the inability to drive or be employed.

"...It's pretty much the unpredictability of the whole situation and being that you have family, you have a fear of not really being there for them"

"I'm ashamed of it often. I don't like that it makes me feel different and that I am different because of it. I don't like the limitations it puts on my life and I don't like the lack of control I feel like I have when I have seizures."

4. *Disclosure of condition.* Some participants felt that if they revealed their condition, other people would judge them:

“My main place that I hide it at is on my job—my supervisor is aware that I have them but the other coworkers, I don’t let them know because I don’t want them surrounding me as if I’m incapable of taking care of my duties at my job.”

Additionally, some felt apprehensive in disclosing their condition to others because of how they were treated in the past when they’d disclosed it. Upon revealing their condition, participants said that they saw a change in both personal and work relationships.

5. *On UPLIFT*. In addition to asking about their experiences in living with epilepsy, participants were presented with components of UPLIFT during focus groups, and feedback was elicited. Overall, most participants agreed that the program would be useful and that they would be interested in participating:

“I think all of these are nice little anecdotes just to help you become more relaxed so you can control your thinking. This is not the first time I’ve heard of any of these things, and I never thought of them as ways to help my epilepsy. I just thought of them as ways to help me as a person, to help me be a better person, you know the exercises like this. So, I can’t see how it could hurt if I tried to relate it to the epilepsy.”

“... like if your seizures are triggered by stress or anxiety. I can see them being useful.”

“I do like some of the ideas that are in here. It doesn’t have any side effects. That’s the good part that I like about it.”

Others were excited about the opportunity to engage in UPLIFT as a group, interacting with others living with epilepsy:

“I think it’s good just to be able to talk amongst other people who have the same (condition). I never talk to anybody else in my whole life that’s had epilepsy to hear -- I don’t know anyone else in my life that has epilepsy. So, just to hear other people who have some of the same kind of issues I have to me that’s kind of comforting just to know that I’m not alone out there.”

Aside from affirming that UPLIFT and its exercises might be helpful, a couple of participants had suggestions for potential changes to the intervention, indicating that it might be useful to replace the poem “The Guest House” by Rumi with “Mother to Son” by Langston Hughes. Although some interpreted the messages to be similar, participants voiced their views on whether they preferred one poem over the other. After presenting the options of both poems to the remaining focus group for persons with epilepsy and having additional participants present their views, the decision was to keep “The Guest House” in the UPLIFT intervention.

Support Person Focus Group Themes

1. *Lack of knowledge about epilepsy*. Support persons seemed to think that more communication about epilepsy was needed in the community, particularly in regard to ways that they could help the person they supported.

“I was not offered any guidance in how to handle seizures. My son, like I said, was injured when he was 15 and he began having seizures a year later, very scary, only from what I’d seen on TV or whatever, you know it -- I was like immobilized through the whole thing just trying to make sure he didn’t hurt himself and hurt me in the process. So, I sought out my own education on how to handle it. I mean even prompting the doctor to tell me okay how do I handle this without him volunteering that information to me, and that kind of upset me, but I realized that it was my problem and not his. So, self-education got me more comfortable with [what] to do.”

2. *Perceived gaps in knowledge of information and resources*. Participants mentioned that more information on support services should be available to the main support person and that there should be more communication between support persons and healthcare professionals regarding where to find those services.

“Well, with me I sure would like to know more about what help that I can get and not so much financially but supportively, you know, like I heard one of the ladies saying they had to go to the day groups.”

“...it sounds like if there was some interdisciplinary communication between the professionals and then those pieces of information were shared with the support people.”

3. *Mental health concerns, including anxiety and depression*. Participants stated that seeing a loved one experience such a demanding and debilitating condition as epilepsy can be stressful for them. The trauma of the condition not only affects the person with epilepsy but also the person providing support.

“But I’ve watched it progress from having seizures several times a day then down to several times a week. And now it’s once a month and sometimes so intense it’s like oh my God you know go on and just take him. I can’t deal with this anymore.”

4. *Worry related to lack of control*. Support persons were also concerned with the lack of seizure control the person with epilepsy experienced. Many worried that a seizure might take place at a time they were unable to assist or when their safety might be at risk.

“Because she couldn’t drive she would take public transportation. So, as a kid, I’m scared that something has happened on the bus if she’s 10 minutes late. You know just getting there. I probably ate the stress away.”

5. *On UPLIFT.* As with persons with epilepsy, support persons participating in focus groups were presented with components of UPLIFT and asked to provide formative feedback about whether the program might be useful for persons like those they supported. Most agreed that the program might be helpful for African Americans with epilepsy and perhaps for themselves. Others expressed concerns about whether it would be best delivered by phone:

“The reason I said I would continue to do this after I got the packet and I read it and I was reading out loud to my husband, I was like oh my god that’s him. Oh my god that’s me. I need it so maybe it’s going to help me too. So, it really –it hit home. I read the whole thing.”

“That’s great but I think that being in a setting like this here [in-person focus group] is more helpful because they can be distracted wherever they are and miss something very valuable.”

DISCUSSION

Evidence-based programs are considered to be most effective in enhancing health promoting behaviors (Green & Tones, 1999). UPLIFT, an evidence-based, self-management program for epilepsy, is efficacious in preventing and reducing symptoms of depression among populations in which African Americans have previously been in the minority (Thompson et al., 2010; Thompson et al., 2015). The present research adds to data on the psychosocial concerns of this group from perspectives that are not currently represented in literature reports. Additionally, it allowed us to determine if UPLIFT was an acceptable program for this community and if modifications needed to be made to assure cultural appropriateness.

CABs can be helpful for tailoring interventions and leading the development of best practices for engaging target communities. The E-CAB was involved in determining how to engage the African American epilepsy community, a group for which little is known. The members of the E-CAB served in expert capacities, providing information, suggestions, and guidance from the perspective of the target community. In E-CAB meetings, we learned more about the role of support persons for African Americans living with epilepsy. Corroborating previous literature in this area, the E-CAB informed us that social support is necessary for this group (Paschal et al., 2005) but that the language used to describe it should not be limiting or decrease the sense of independence of the person with epilepsy. As revealed in the focus groups, loss of independence may be particularly difficult for African Americans living with epilepsy. Additionally, we learned that we should be as inclusive as

possible in our criteria for enrolling African Americans with ‘epilepsy,’ as some may not identify the condition in this manner. As a result, all recruitment materials were updated to reflect the recommended language. In the future, we will use such language in recruiting African Americans for adaptation of other epilepsy self-management programs.

Understanding the experiences of African Americans with epilepsy from the healthcare provider perspective provided a lens for learning about the healthcare needs of this understudied population. We originally planned to interview healthcare providers only about ways to recruit African Americans with epilepsy. However, since health and healthcare outcomes vary across racial groups within the epilepsy community, we determined that it would be best to gain insight on the experiences of care providers for this population. Although the sample size was small and caution should be used in making generalizations from the data collected, the interviews with healthcare providers yielded information about the challenges facing the population of interest. In particular, these providers shared differences between their African American and Caucasian epilepsy patients. Two relevant differences were the negative perceptions surrounding mental health conditions and the mistrust of the healthcare system in the African American community. Some African Americans believe that seeking mental healthcare might make them appear “crazy,” which illuminates, for this group, the prevailing stigma and stereotypes surrounding epilepsy and mental illness. The providers also shared their insights on the utilization of UPLIFT as an intervention for this population of epilepsy patients. Their observations illustrate the importance of engaging in direct formative work with this community to learn how to address their needs effectively and to assess if and how existing evidence-based programs such as UPLIFT might be beneficial.

Focus group participants provided feedback contextualizing responses from the E-CAB and healthcare provider interviews. Participants discussed experiences with epilepsy as well as their self-management efforts with limited knowledge and resources. As found in a previous study of African American female epilepsy patients (Paschal et al., 2005), both focus group participants living with epilepsy and their support persons shared that there was a lack of knowledge about epilepsy and resources available for the African American epilepsy community. Furthermore, participants desired information about how to manage their condition and how to be a better support provider for their loved ones. Such perceptions and gaps in knowledge contribute to stigma and likely to the propensity of African Americans with epilepsy to avoid engaging appropriate resources. These are concerns demonstrated in previous reports (Bautista, Glen, Shetty, & Wludyka, 2009; Bautista, Shapovalov, Saada, & Pizzi, 2014; de Boer, Mula, & Sander, 2008).

Many of the focus groups participants with epilepsy discussed experiences related to depression and feelings of hopelessness and defeat. These findings are similar to those

of other chronically ill populations (Simon, 2001). Further enlightening was learning about the mental and emotional state of their support persons, many of whom experienced chronic stress, anxiety, and worry as a result of supporting someone with epilepsy. Based on these findings and lessons learned, as well as feedback about UPLIFT components, where the extent of suggestions for modification were focused on one poem and its distance delivery format, UPLIFT might be both acceptable and beneficial to African Americans with epilepsy and perhaps to those who provide them with support. The next steps are to engage in a randomized, controlled trial evaluating the efficacy of UPLIFT for African Americans with epilepsy and further assessing the acceptability and feasibility of the program with this population.

CONCLUSIONS

The contributions of each of the three research strategies described in this report are substantial. Notably, the E-CAB was essential for decision-making, as it related to best strategies for engaging the African American epilepsy community and the potential utility of UPLIFT for this population. A diverse group of healthcare providers provided their perspectives on ways in which the experiences of the African American epilepsy community might differ from those of other racial groups. African Americans with epilepsy and their support persons generally felt that UPLIFT could be beneficial to their community. There were no major concerns with UPLIFT program materials; therefore, no substantive changes were needed. A randomized-controlled trial of UPLIFT with the African American community will begin soon.

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