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## Depression self-management in people with epilepsy: Adapting project UPLIFT for underserved populations

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### Abstract

Data from the 2015 National Health Interview Survey found that the prevalence of active epilepsy has increased to three million adults. Although findings have been mixed, some research indicates that Blacks and Hispanics share a higher burden of epilepsy prevalence compared with non-Hispanic whites. Moreover, depression is a common comorbid condition among people with epilepsy (PWE), affecting up to 55% of the epilepsy population. Widespread use and increased public health impact of evidence-based self-management interventions is critical to reducing disease burden and may require adapting original interventions into more culturally relevant versions for racial and ethnic minority groups. Project UPLIFT provides access to mental health self-management skills training that is distance-delivered, does not interfere with medication management, and has been shown to be effective in reducing depressive symptoms. This paper presents the process of exploring the adaptation of Project UPLIFT for Black and Hispanic PWE and herein suggests that evidence-based interventions can be successfully adapted for new populations or cultural settings through a careful and systematic process. Additional key lessons learned include the importance of community engagement and that language matters. Ultimately, if the adapted Project UPLIFT intervention produces positive outcomes for diverse populations of PWE, it will extend the strategies available to reduce the burden of depression. Implementing evidence-based interventions such as Project UPLIFT is critical to reducing disease burden; however, their delivery may need to be tailored to the needs and culture of the populations of interest.

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None.

## Keywords

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## 1. Introduction

The purpose of this paper is to describe the methods used to explore the need to culturally adapt Project UPLIFT, an evidence-based mental health intervention for depression in people with epilepsy (PWE). Sharing of these adaptation processes may assist others in adapting evidence-based programs for new audiences.

### 1.1. Epilepsy and special populations

Data from the 2015 National Health Interview Survey found that the prevalence of active epilepsy had increased from the previous estimate of 2.3 million adults in 2010 to three million adults [1]. Although findings have been mixed, nationally, epilepsy incidence, prevalence, and mortality rates are similar in non-Hispanic Blacks, Hispanics, and non-Hispanic Whites [2–4]. However, several smaller, local studies have found that Blacks and Hispanics have an increased prevalence of epilepsy [3,5–7]. Kroner and colleagues [6] found that Blacks living in Washington, D.C. had lifetime prevalence and active epilepsy prevalence rates that were double that of their White counterparts after adjusting for age and education. Similarly, a study conducted in New York City’s Harlem neighborhood found a higher epilepsy prevalence in Hispanics than in non-Hispanic Whites [5]. Unfortunately, the stigma associated with epilepsy may contribute to underreporting in population-based surveys. For example, a 2006 survey by the Epilepsy Foundation found that many Hispanics in the U.S. are fearful of epilepsy and unwilling to disclose epilepsy in a family member [8].

Health service utilization also differs by race among people with epilepsy. Self-reported interview findings indicate that when compared with Whites, Blacks had five times more care from generalists and 70% fewer specialist visits after controlling for seizure frequency and other chronic conditions [9]. They also had greater than three times more visits to emergency departments (ED) and five times more hospitalizations than Whites. Begley and colleagues [9] proposed that ED visits and hospitalizations suggest lower quality of care for Blacks. Hispanics, like Blacks, experience significant disparities in healthcare access and health outcomes across a broad range of chronic diseases, including epilepsy [10,11]. For example, diagnosis of epilepsy in an ED was more common for Hispanics and Blacks than for non-Hispanic Whites in a New York City sample [5]. The language barrier, along with differing cultural values, belief systems, and stigma, all contribute to reduced healthcare utilization among Hispanics [12–14]. Approximately half of Hispanic Americans have limited English proficiency (i.e., report speaking English less than “very well”), and the rate is higher in the foreign-born population [15]. Therefore, programs that address the challenges that Blacks and Hispanics face in regard to healthcare are needed.

## 1.2. Epilepsy and depression

Depression, a common comorbid psychiatric disorder among PWE, more strongly predicts reduced quality of life than seizure frequency [16–19]. Suicide rates among PWE are 22% higher than among the general population, with an estimated average annual suicide rate of 16.89/100,000 among PWE compared with 13.84/100,00 in the general population [20,21]. Moreover, people with both epilepsy and depression report higher levels of perceived seizure severity [18]. In addition, attention should be given to the double stigma associated with the comorbid condition of depression with epilepsy among minority populations as an underlying factor in poorer health outcomes [16,18,22,23]. The interaction of these two effects within marginalized populations may be an underlying contributor to poorer health outcomes in these populations.

Unfortunately, despite poorer health outcomes, depression often goes unrecognized and undertreated among PWE [24,25]. Cultural dynamics may play an important role in undertreatment of mental illness among Blacks and Hispanics. Blacks and Hispanics reporting serious psychological distress remain less likely to receive mental health treatment than Whites [26]. Among Blacks, previous studies have found that their attitudes and beliefs regarding mental illness and depression stem from a mistrust of mental health treatment and providers, and that depression is conceptualized as a weakness [27,28]. Among Hispanics, those with elevated depressive symptoms are more likely to prefer counseling instead of medication than Whites [29,30]. However, their adherence to psychotherapy is often poor [31], which may reflect a lack of cultural tailoring of standardized psychotherapeutic interventions. Limited English proficiency contributes to this problem and also contributes to psychological distress [32]. Therefore, any successful treatment for depression among Black and Hispanic PWE will need to consider the perceptions listed above, along with the impact of a double stigma, i.e., epilepsy and depression.

## 1.3. Project UPLIFT

Designed to address depression, reduced access to mental healthcare, and concerns about psychotropic medications among people with chronic illnesses such as epilepsy, Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) provides group distance delivery of mental health self-management skills training. Group delivery was deemed an important component of the program because isolation can be a problem for people with chronic diseases like epilepsy, and social support is often lacking [33]. Thompson and colleagues [34] developed Project UPLIFT for use as a home-based depression treatment for PWE, and later extended it for use in prevention of depression among PWE [35].

The program content is based upon mindfulness-based cognitive therapy [36] and includes modules for eight weekly sessions: 1) Monitoring Thoughts, 2) Challenging and Changing Thoughts, 3) Coping and Relaxing, 4) Attention and Mindfulness, 5) The Calm Present, 6) Thoughts as Changeable, Thoughts as Impermanent, 7) Focus on Pleasure and the Importance of Reinforcement, and 8) Preventing Relapse and Giving Thanks. Cognitive skills targeted by program activities include thought monitoring and reality checks, as well as coping strategies and mindful attention. Specific mindfulness skills addressed by program

activities include mindfulness of sights, sounds, and thoughts in everyday activities and other meditations. Sessions are designed to be 1 hour in length on the phone and are comprised of a check-in period, teaching on the topic of that week's skill, group discussion, a skill-building exercise, and a home practice assignment. Participants receive a workbook of materials for each module.

Thompson and colleagues [34,35] evaluated Project UPLIFT utilizing randomized controlled trials to assess the program's acceptability and effectiveness in treating depressive symptoms [34] and preventing the onset of major depressive disorder [35] among PWE, relative to treatment-as-usual (TAU) waitlist control groups. For the treatment randomized controlled trial (RCT), participants who screened positive for mild to severe depression were included in the study. For the prevention RCT, study participants were required to have symptoms of depression (i.e., an *absence* of moderate-to-severe depressive symptoms) and no evidence of Major Depressive Disorder as determined by the Patient Health Questionnaire-9 (PHQ-9) [37]. For both trials, a Project UPLIFT trained facilitator and a PWE cofacilitator presented information and led activities. There was no difference between delivery by web and by telephone, so the groups were combined in subsequent analyses. In the treatment RCT, scores on a measure of knowledge and skills related to depression, mindfulness, and cognitive behavioral therapy increased significantly more, and depressive symptoms decreased significantly more in Project UPLIFT versus TAU, both immediate postintervention and after 8-weeks of follow-up [34,35]. In the prevention RCT, the incidence of new or relapsed cases of major depressive disorder was significantly lower among those participating in Project UPLIFT groups than among those receiving TAU. Depressive symptoms decreased significantly more among the Project UPLIFT group than among those receiving TAU, and the effect was mediated by the increase in knowledge and skills. In addition to knowledge and skills, satisfaction with life also increased significantly more in the Project UPLIFT group than the TAU group [34,35].

Since the development of Project UPLIFT, Thompson and colleagues have been disseminating the telephone version of this program for PWE. Dissemination is limited to the telephone version because web-based intervention does not reach many PWE; i.e., PWE are un- and underemployed at higher rates than those in the general population [38], which can lead to limited computer or Internet access. Moreover, maintaining a web-based program through updates and changes in operating systems increases the cost of the program. To date, trained telephone facilitators are available in 33 states (see <https://managingepilepsywell.org/uplift>), but the program is only available in English, leaving an enormous group of patients in need without access.

Thompson and colleagues in the Managing Epilepsy Well (MEW) Network were funded by the CDC in 2014 to conduct research to ensure that Project UPLIFT is culturally appropriate for Black and Hispanic PWE populations. Cultural differences in health beliefs and behaviors exist between Whites, who constituted the majority of the original populations in which Project UPLIFT was tested, and Blacks and Hispanics with epilepsy. Furthermore, mindfulness-based interventions have been shown to be effective in racial and ethnic minority groups [39, 40], but delivery in languages other than English has been limited. There is a need to develop mental health programs that can be delivered in Spanish to

Hispanic Americans to enhance engagement and efficacy [41–43]. Taking these factors into account, the Morehouse School of Medicine (MSM) MEW Network team sought to examine the potential need for cultural adaptation of Project UPLIFT for Black PWE. Similarly, the aim of the New York University (NYU) School of Medicine MEW Network team was to translate and culturally adapt Project UPLIFT for Hispanic PWE.

#### 1.4. Evidence-based interventions and program adaptation

Moving evidence-based interventions into local practice is essential to improving the public's health [44]. An evidence-based intervention (EBI) often starts with an efficacy study, followed by effectiveness studies, and then it is taken to scale and implemented in population settings [45]. Implementation science studies have found that organizations frequently make changes to the original EBI in order to fit the needs of their community and the capacity of their organization [46–48]. Current research is exploring what happens once community organizations adapt EBIs, including how they identify appropriate EBIs and how they change the EBI to suit their needs [49]. Adaptation is often defined as modifications of existing program components, changes in the manner or intensity of components, or cultural modifications to best fit local communities or circumstances [50].

Within program adaptation, cultural adaptations are sometimes made in an effort to have an EBI better fit with an audience's ethnicity and/or culture. Bernal and colleagues defined cultural adaptation as the systematic modification of an EBI "to consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meanings, and values" (p. 362) [51]. Two types of adaptations, surface and deep structure, can be made [41]. Surface structure adaptations involve matching program materials, content, or messages to the characteristics of an intended audience, such as using images of people, language, or settings familiar to the audience. Conversely, deep structure adaptations involve incorporating the cultural, psychological, and historical factors that impact the health behavior of the intended audience, such as their motivations or reasons for change. The benefits of cultural adaptation are to increase the ecological validity of these programs, generalizability in real world settings, and to reduce health disparities by increasing access to these adapted programs [52]. In a recent scoping study (i.e., review of the literature) of frameworks that offers guidance in conducting program adaptations, Escoffery and colleagues [53] identified 11 common steps across the adaptation frameworks: 1) assess community, 2) understand the EBI(s), 3) select the EBI, 4) consult with experts, 5) consult with stakeholders, 6) decide on needed adaptations, 7) adapt the original EBI, 8) train staff on the EBI, 9) test the adapted materials, 10) implement, and 11) evaluate the adapted EBI.

The methods described below were used to explore the need for cultural adaptation of Project UPLIFT for two different populations with epilepsy; and lessons learned from that process.

## 2. Methods

We describe the adaptation process used by the two teams below. We utilized a case study approach to describe the steps outlined using an adaptation framework for the MSM and

NYU Project UPLIFT studies. IRB approval was received from MSM and NYU, and informed consent was obtained for all focus group and interview participants.

## 2.1. Adaptation for blacks

**2.1.1. Consult with experts**—During the first phase of the MSM study, we employed community-engagement and qualitative methods to explore experiences and perspectives regarding epilepsy, the associated stigma, self-management behaviors, and Project UPLIFT for Black PWE.

**2.1.1.1. Development of the Epilepsy Community Advisory Board (E-CAB):** Community advisory boards (CABs) are a recommended tool for involving communities in community-engaged research aimed at reducing health-related disparities associated with chronic diseases [54]. Community advisory boards provide a mechanism to facilitate the community-academic relationship and provide feedback between partnering groups [55]. Black PWE belong to two distinct groups, both of which are marginalized and stigmatized [56,57]. 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 caregivers; and the healthcare providers for this subgroup. These perspectives were necessary in providing the research team with knowledge of how best to adapt Project UPLIFT.

To construct the E-CAB, the MSM research team recruited individuals using a purposive methodology with the intention of selecting between 7 and 10 members [58]. Inclusion criteria for potential E-CAB members included 1) self-identify as a Black PWE; 2) self-identify as a caregiver or main support person (MSP) of a Black PWE; 3) a healthcare professional serving Black PWE; and 4) a community advocate for either the Black community or epilepsy community. During the first 1215 months of the project, the E-CAB met monthly to address the goals of the project. The E-CAB: 1) was presented with the Project UPLIFT Facilitator Manual and participated in mock intervention sessions; and 2) evaluated the intervention based on criteria for appropriateness of the content. Content appropriateness was explored with regard to: a) literacy; b) language perspective; c) content organization; d) message construction (clarity, consistency, main points, tone, appeal and credibility); and e) cultural sensitivity.

**2.1.1.2. Healthcare provider interviews:** Healthcare providers living in Georgia with experience treating Black PWE were interviewed. These providers were recruited through snowball sampling methods via our E-CAB members and other community partners. The study sample consisted of diverse healthcare providers who identified as: chiropractor, nurse practitioner, psychologist, neurologist, and epileptologist. In interviews, providers were asked about their perspective on the experiences of their Black patients with epilepsy. The providers presented psychosocial concerns that they frequently encountered with Black PWE regarding the experience of stigma, anxiety and depression, concerns about productivity, access to quality care, and social support. They also gave their perspectives on ways in which the experiences of the Black epilepsy community might differ from those of other racial groups.

## 2.1.2. Consult with stakeholders

**2.1.2.1. Focus groups with PWE and MSP:** In addition to engaging the E-CAB and healthcare providers, we also conducted focus groups. Two groups were targeted for participation: Black PWE and MSP for Black PWE. Those with epilepsy were recruited to participate in focus groups if they: 1) self-identified as African American or Black; 2) diagnosed with epilepsy or seizure disorder at least three months prior; 3) were a Georgia resident; 4) were at least 18 years of age or older; 5) were English-speaking; 6) were mentally stable with no reported plans or intent for suicide; 7) were willing to attend a two-hour focus group discussion; and 8) were willing to be audio-recorded during focus group discussions. Main support persons were eligible to participate in focus groups if they supported a PWE that: self-identified as African American or Black; was diagnosed with epilepsy at least three months prior; and was a Georgia resident at least 18 years of age or older. The MSP also had to be: 1) English-speaking; 2) mentally stable with no reported plans or intent for suicide; 3) willing to attend a two-hour focus group; and 4) willing to be audio-recorded during focus group discussions.

A total of six focus groups were conducted (four PWE and two MSP). For those with epilepsy, there was one in-person focus group, and three focus groups were conducted over the telephone. The telephone focus group option was open to each participant if transportation or participation in a face-to-face focus group was not convenient or easily accessible. Although telephone focus groups limit the ability to read nonverbal behavior, they provide a viable alternative to face-to-face focus groups [59]. For PWE, transportation is a common barrier due to 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. It was also helpful to hold a face-to-face focus group for the PWE and MSP, in the same location and time period to facilitate transportation. Both face-to-face and telephone focus groups were facilitated by a Black research team member and cofacilitated by a Black MSP. All focus groups lasted approximately 2 h. Participants received a \$50 gift card for participation. Discussions focused on knowledge and perceptions of epilepsy in the Black community, epilepsy stigma, and epilepsy self-management behaviors. Selected sections of the Project UPLIFT manual and mindfulness exercises were also reviewed during the focus groups. Focus group results have been published elsewhere [58]. Briefly, the PWE focus groups (N = 22) consisted of 68% women with age range: 20–83 years. The MSP focus groups (N = 13), consisted of 100% women with age range: 45–66 years [58].

## 2.2. Adaptation for hispanics

**2.2.1. Consult with experts—**During the first phase of the NYU study, Project UPLIFT was adapted using a rigorous qualitative process conducted in collaboration with Hispanic PWE and academic and community partners. Because language is only one aspect of cultural adaptation, the goal of this process was to develop new English and Spanish versions of all study materials, rather than using the existing English versions for any Hispanic patients who preferred to communicate in English. After translating all study

materials into Spanish using a professional translation service, we engaged an expert consultant with more than 20 years of experience delivering mindfulness-based interventions to Hispanic communities to assist with the adaptation process. The NYU team sent all Project UPLIFT materials to this expert for review, and he provided detailed written feedback, and we discussed his suggestions for revisions together in a series of conference calls. He also audio-recorded all meditation exercises used with the ‘on your own practice’ assignments in Spanish. NYU-affiliated epileptologists (N = 4) and psychiatrists (N = 2) caring for Hispanic PWE were also interviewed to gather feedback on the need for adaptation and the planned study methods.

**2.2.2. Consult with stakeholders**—Next, focus groups and individual interviews were conducted to gather feedback about Project UPLIFT and the adapted program materials. Participants were recruited from Bellevue Hospital Center, NYU Langone’s Comprehensive Epilepsy Center (CEC), and NYU Langone Hospital-Brooklyn. Eligibility criteria for participation were: 1) 21 years of age and older; 2) self-identified as Hispanic; 3) English or Spanish speaking; 4) diagnosis of epilepsy and at least one-year post diagnosis; 5) willing to attend a 2-hour focus group and/or a 30- to 45-minute cognitive interview at Bellevue Hospital, CEC or NYU Lutheran; and 6) willing to be audio-taped. Focus groups and individual interviews were conducted in English or Spanish by trained Hispanic facilitators using a structured set of open-ended questions regarding patients’ knowledge and beliefs about epilepsy and depression, cultural attitudes and norms, and needs and barriers to mood management. Selected sections of the Project UPLIFT Manual and mindfulness exercises were presented to patients to ascertain their relevance, appeal and understandability. Patients received \$40 for participating in focus groups or cognitive interviews.

Three focus groups were conducted (two in Spanish, one in English) with a total of 11 patients (100% Hispanics/Latinos; age range: 26–51 years; 57% female). In addition, six cognitive interviews were conducted with individual participants, three of whom also participated in a focus group. In two of these interviews, the PWE was accompanied by an MSP who also participated in the interview. Focus groups were transcribed and translated, if needed, and participants’ feedback regarding the intervention was summarized and reviewed as a team before incorporating it into the adapted English and Spanish Project UPLIFT materials.

### 3. Results

The results of the adaptation process for Project UPLIFT demonstrate several methods for adapting the intervention for two distinct cultural groups.

#### 3.1. Blacks

The E-CAB was instrumental in identifying the appropriate language and approach for soliciting participants for focus groups and provided feedback on Project UPLIFT activities. Epilepsy Community Advisory Board members recommended that we change our language and replace “caregiver” with “support person” to describe persons who help adult PWE. They stated that for some Blacks, the term “caregiver” implies that the PWE is unable to care for him/herself. In contrast, the term “support person” implies that someone is assisting



the PWE to care for themselves, typically through providing instrumental support. This finding corroborates previous reports in which instrumental support, such as transportation to appointments or picking up medication, is essential for Blacks living with epilepsy [60].

Additionally, E-CAB members suggested that the language on study documents be expanded to “epilepsy or seizure disorder” to accommodate those who might not feel comfortable identifying their condition as “epilepsy” or who may understand their diagnosis as “seizure disorder” but are not aware of or may not remember whether the diagnosis of epilepsy was explicitly stated. This change is also supported by past research that found that 75% of respondents who had a history of epilepsy identified their condition as a seizure disorder rather than epilepsy [61]. Modifications to all recruitment documents were made based on the above suggestions.

Lastly, the E-CAB assisted in the interpretation of the focus group and cognitive interview findings and was critical in the decision of whether to adapt Project UPLIFT. Proposed themes from the qualitative analysis of the focus group and cognitive interview transcripts were presented and discussed during several E-CAB meetings. In addition, any challenges or questions arising from the formative research stage of the study were also brought to the E-CAB for input and guidance.

Healthcare providers, in addition to being asked to share their experiences in providing care to Black PWE, were also briefly introduced to Project UPLIFT and asked to share their opinions of the intervention and their opinion of how their Black patients with epilepsy would respond to it. All five providers stated that they believed that their patients would benefit from participating in Project UPLIFT.

Overall, most focus group participants agreed that Project UPLIFT would be useful and that they would be interested in participating. Participants were excited about the opportunity to engage in Project UPLIFT as a group, interacting with others living with epilepsy. Main support person participants noted that the program may also be helpful for them. Aside from affirming that Project UPLIFT and its exercises might be helpful, a couple of MSP participants suggested potential changes to a particular Project UPLIFT session, indicating that it might be useful to replace the poem “The Guest House,” by Rumi, with “Mother to Son,” by Langston Hughes, an African American Poet. In the Hughes poem, a mother uses the metaphor of an old staircase to describe her life challenges and to encourage her son to persevere. The Rumi poem is often used in the context of mindfulness practice and uses the metaphor of a guest house to encourage the reader to welcome ‘unpleasant’ and/or unexpected thoughts, emotions, and bodily sensations just as they would a guest coming to their home. Although some interpreted the messages conveyed by each poem to be similar and/or were indifferent, others voiced preference for the Rumi poem. After presenting both of the poems to the remaining PWE focus groups and seeking input from the E-CAB, the decision was made to keep “The Guest House” poem. One PWE participant aptly summarized our decision in their comment:

If I’m not in a good place, then that’s not something I really want to hear [Mother to Son Poem]. I don’t really want to hear about the struggle. I want my mind to be

taken away from that. I don't know. That doesn't do anything for me. But, I like the poem. I just don't like it for what we're trying to address.

Additionally, some MSP participants and healthcare providers voiced concerns about delivering Project UPLIFT 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. However, as mentioned earlier, transportation is a significant barrier for PWE, which is why Project UPLIFT was specifically designed to be distance delivered. It is interesting to note that no PWE focus group participants shared this concern. Selected quotes from PWE and MSP focus group participants regarding the perceived need for Project UPLIFT, and feedback about the program are presented in Tables 1 and 2.

The insight gained from this community-engaged approach was substantial. Notably, the E-CAB was essential for decision-making, as it related the best strategies for engaging the Black epilepsy community and the potential utility of Project UPLIFT for this population. Black PWE and their MSP generally felt that Project UPLIFT could be beneficial to their community. There were no major concerns with Project UPLIFT program materials; therefore, no substantive changes were needed.

### 3.2. Hispanics

The providers who were interviewed emphasized the importance of involving family members in the recruitment process and framing epilepsy and depression as disorders that affect the entire family, highlighting potential benefits of reducing depression for both the individual and the family. They also recommended using Hispanic (not simply bilingual) research staff and intervention facilitators. This is consistent with evidence that ethnic matching of provider is associated with longer treatment duration and better treatment response in Hispanics and that using *promotoras* to deliver interventions is effective [69].

Preliminary adaptations were made to the Project UPLIFT materials based on a review of the literature regarding relevant cultural factors and input from our expert mindfulness consultant. These adaptations included reducing the literacy level (e.g., shorter sentences, simpler vocabulary) and reducing the amount of text on each page. These changes were reflected in both the Spanish and the adapted English versions of the Project UPLIFT materials. With regard to content, we considered replacing the segment of "Forget about enlightenment", a poem by John Welwood that is commonly used in mindfulness programs, with "Last night, as I was sleeping", by Antonio Machado, a Spanish poet. When presented with both options in the subsequent focus groups, participants did not have a strong preference, so we kept the original poem (in English and Spanish) because we felt it better conveyed the intended message.

Further adaptations were informed by feedback from the focus groups and individual interviews. A major focus was refining the initial Spanish translation to improve clarity and relatability to the Hispanic population. Words considered too "proper" by participants were replaced with more commonly used Spanish words. In light of participants' confusion regarding the initial translation of "mindfulness" as "conciencia plena" (awareness), our

consultant recommended replacing it with “atencion plena” (attention), which was positively received by participants. They also replaced second-person pronouns with first-person plural pronouns, which is perceived as less directive and is consistent with the cultural value of *personalismo* (i.e., formal friendliness) [71]. For example, the instruction to “concentrate on your feet” was changed to “let’s bring our attention to the feet” in both Spanish and adapted English versions of the Project UPLIFT materials.

Selected quotes from participants regarding the perceived need for Project UPLIFT and feedback about the program are presented in Table 3. Participants discussed the importance of family and social connection in managing their epilepsy, and how stigma associated with epilepsy leads to social isolation. They described an awareness of the impact of depression, anxiety, and stress on their epilepsy and a desire for help in managing these emotions. Interestingly, some noted parallels between meditation and prayer, but none expressed concerns about how Project UPLIFT might conflict with their religion. While feedback was largely positive, many focus group participants expressed a preference for in-person sessions because they felt they would not be able to connect with other group members over the telephone. We chose not to incorporate in-person contact because Project UPLIFT was specifically designed to address transportation barriers among PWE and doing so would reduce scalability of the program. However, this feedback was important in alerting the study team to the need to proactively address this issue during recruitment so that the benefits of Project UPLIFT could be emphasized (i.e., the unique opportunity to interact with other Hispanic PWE).

## 4. Discussion

### 4.1. Summary

The aim of this manuscript was to describe the adaptation process of Project UPLIFT for Black and Hispanic PWE. The Adaptation framework outlined by Escoffery and colleagues [53] was generally followed and based on input from experts and stakeholders, each site implemented modifications. The MSM team found that no changes were necessary for the Project UPLIFT curriculum itself, however, recruitment language needed to be slightly modified for Black PWE. On the other hand, the NYU team found that in addition to language translation, certain concepts within the curriculum needed to be modified for Hispanic PWE in both the Spanish and adapted English versions of the Project UPLIFT materials. As a result of this adaptation process, there were three key lessons learned across both teams that may be helpful for future EBI adaptations.

### 4.2. Lessons learned

First, a systematic process for making adaptations is important, as well as documentation of those steps. Adaptation of programs often focuses only on the intervention content itself and not its delivery. In this adaptation process, both MSM and NYU learned that it was important to explore the need to adapt the program’s curriculum but also to examine how best to deliver the proposed EBI in the new community. The review by Escoffery and colleagues [53] suggested common steps undertaken in the adaptation process for EBIs. In the current paper, the MSM and NYU teams described the processes from the point of

intervention selection (step #3) through implementation and evaluation of the adapted EBIs (step #11). The adaptation documentation and pilot RCTs of the adapted implementation of Project UPLIFT can inform future dissemination efforts and share with others how to make adaptations and improve intervention outcomes.

Second, community engagement is essential. Both sites engaged community stakeholders throughout the adaptation process and found their input to be invaluable. Both teams conducted focus groups and interviews to learn the needs of their community and gather feedback to inform changes to the program materials. This process proved to be crucial considering that the assumptions of the research team were sometimes disproved. For example, the NYU team expected Hispanic PWE to prefer a poem authored by a Spanish poet, which was not the case. Likewise, while Black MSP suggested changing one of the poems, the MSM team received feedback from the target population itself, Black PWE, that they related to the poem included in the Project UPLIFT materials. Community engagement also proved important in getting the language right for both recruitment and delivery. While the MSM team learned the preference of Black PWE for terms like “seizure disorder” and “support person” over “epilepsy” and “caregiver”, the NYU team learned to avoid formal Spanish grammar and to simplify descriptions of mindfulness in both languages. Additionally, the NYU team learned that the preference of Hispanic PWE for in-person groups must be directly addressed in order to successfully recruit for the RCT. Rather than incorporating in-person contact, which was deliberately excluded from Project UPLIFT to enhance access for PWE, recruitment conversations with prospective RCT participants emphasized the practical advantages of a home-based program. The NYU team also incorporated feedback concerning the strong desire for connection with other PWE by highlighting the fact that participating in Project UPLIFT would provide a rare opportunity to interact with other Hispanic PWE. These findings underline the importance of a formative phase of community assessment, which is recommended by many existing adaptation frameworks [62–64].

Lastly, language is important. Consultation with the program developers and stakeholders was an integral part of making decisions about which modifications were necessary to ensure that the program content and delivery are relevant to each new community. Changes were determined based on basic fit with the population and cultural understanding of terms used in the intervention delivery (e.g., mindfulness). With the adaptation for Hispanics, translation into Spanish as well as cultural interpretation of the intention of the program’s wording was critical. With the Hispanic population, cultural adaptations were not just surface level but also focused on making changes to wording due to cultural understanding of English phrases important to the intervention strategies of mindfulness. Similarly, with the adaptation for Blacks, we were advised on the importance of word choice in recruitment advertising. However, Black PWE required no cultural adaptation for the Project UPLIFT materials. Engagement with all stakeholders is critical in making decisions about adaptations. Adaptations to the Project UPLIFT curriculum or in recruitment advertisements were the result of systematic engagement through guidance of community experts (E-CAB or community consultants), focus groups, and cognitive interviews.

### 4.3. Limitations

A limitation of our studies is their generalizability. The MSM team included Blacks from Georgia, which may not be generalizable to other Black PWE across the U.S. Similarly, the NYU team included a sample of Hispanic PWE that may not be generalizable to other Hispanic communities across the U.S. The public transportation system in NYC may have contributed to our participants' preference for in-person versus telephone intervention groups, which would be less burdensome than for Hispanic PWE in many other areas. Also, the Hispanic population in NYC is predominantly Puerto Rican and Dominican, whereas Mexicans comprise the largest Hispanic subgroup in most other parts of the U.S. In addition to country of origin, the Hispanic population in the U.S. is extremely heterogeneous with regard to acculturation level, socioeconomic status and documentation status. Although it may not be feasible, or necessary, to tailor mental health programs for each subgroup, continued attention to issues of cultural appropriateness and the possible need for further tailoring is critical.

### 4.4. Future directions

Our next step is the further evaluation of Project UPLIFT in these two populations. Both teams are currently in the process of conducting RCTs to test the feasibility, acceptability, and effects of the intervention. Follow-up data collection for both trials is expected to be complete by August 2019. Recruitment, retention and adherence rates, efficacy data, and feedback from both participants and facilitators may inform of additional modifications to Project UPLIFT after study completion. If these studies support the feasibility, acceptability, and efficacy of the adapted program, Project UPLIFT dissemination can be expanded to Blacks and Hispanics, two large, underserved and hard-to-reach populations of people living with epilepsy. Considering that Hispanics are the largest and fastest growing minority group in the U.S. [15] and the low utilization rates for mental health treatment by both Blacks and Hispanics [65], the potential public health impact is substantial. Future studies could evaluate adapted versions of Project UPLIFT in additional populations (e.g., Asian Americans).

The current RCTs for Blacks and Hispanics being implemented will advance the science of adaptation of EBIs and may bolster the proposition that adapted EBIs can retain the original program's effects or not have diminishing results [66]. The science of cultural adaptations is nascent; more research is needed to understand not only the adaptation process, but also the adoption, recruitment and engagement of diverse communities; and sustainability of adapted EBIs [67]. Furthermore, future studies could focus more on assessment of implementation outcomes (i.e., acceptability, feasibility, and appropriateness from all stakeholders, including implementers and participants) [68]. These factors are related to how aspects of the adapted intervention are viewed and assessed by the new community and setting.

## 5. Conclusion

Evidence-based programs have the potential to improve health outcomes; however, not all are appropriate for all populations. Implementing EBIs such as Project UPLIFT is critical to reducing disease burden; however, their delivery in local communities should be tailored to

the needs and culture of the community of interest. Through a systematic process of adaptation, many EBIs have the potential to extend their reach beyond their original population. Among PWE, depression rates are extremely high, up to 55% [16]. Moreover, there are limited culturally relevant EBIs available to address depression among Blacks and Hispanics with epilepsy. The adaptation projects described above are designed to address this gap. Project UPLIFT provides access to mental healthcare that is distance-delivered, does not interfere with medication management, and has been shown to be effective in reducing depressive symptoms. The adaptation of Project UPLIFT for Blacks and Hispanics with epilepsy described herein suggests that EBIs can be successfully adapted to new populations or cultural settings through a careful and systematic adaptation process. Additional key lessons learned include the importance of community engagement and that language matters. Ultimately, if the adapted Project UPLIFT intervention produces positive outcomes for diverse populations of PWE, it will extend the strategies available to reduce the burden of depression for different populations living with epilepsy.

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**Table 1**Feedback from Black PWE focus group participants.<sup>a</sup>

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**A. Perceived need for project UPLIFT**

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I personally think that's a good technique just because one thing I do notice about myself is that I'm tense but it's kind of like I'm not aware that I'm tense... And then I'll notice like my arms are very like tense or my shoulders are very tense. So, I think being aware could be useful because I think sometimes that tenseness can kind of lead to you feeling kind of stress and then the stress leads to you feeling like you're going to have a seizure.

I think that all of these would be useful for people who, like, if your seizures are triggered by stress or anxiety. I can see them being useful.

So, I think that would be helpful to me and it may be helpful to some other people.

I learned about this when I was in the hospital with my son, [Name], several years back. So, I always do this. I recommend it for everybody, even people without seizures.

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**B. Feedback about Project UPLIFT**

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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...

I like just the fact that it encourages you to slow down and to think about you know how your body's feeling because you tend to be so busy. I don't ever really slow down enough to focus on just the breathing part or you know how things are feeling and how to let go of some of that stressful feeling through just thinking about slowing down and tensing up and feeling how it feels different when you relax. It works for me.

Once the depression is captured or taking care of it could help with stress. It could help with memory, different things that are side effects for epilepsy.

The Guest House kind of sound like epilepsy. "The joy, depression, meanness.... welcome and entertain them all."

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<sup>a</sup>PWE = people with epilepsy.

**Table 2**Feedback from Black MSP focus group participants.<sup>a</sup>**A. Perceived need of Project UPLIFT**

[Pebble Exercise] So, these exercises are good exercises for the people who have epilepsy... Even when it come down to their smell or them touching something, like she saying about the pebble, when you touch something or squeeze something, you know all that's a good exercise for people who do have seizures. Those are excellent exercises. It really is.

.... 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 [child with epilepsy]. 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.

**B. Feedback about Project UPLIFT**

[Enlightenment Poem] I like this. It's positive reinforcement. It's saying to the person that every part of you is a relevant and important part of your total being.

I think the Wild Geese is an example of difference. It tells the individual that yeah you may be different but you're still in the family and you can persevere just like the geese do. I mean they get up and fly and do the things that they need to do. So, although you have this here, you can still persevere. You don't have to let this be a stopping place for you. You can keep on going.

<sup>a</sup>MSP = main support persons.

**Table 3**Feedback from Hispanic PWE focus group participants.<sup>a</sup>

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**A. Perceived need for Project UPLIFT**

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I also know when I am stressed out, bothered, worried, the whole combo, and that's when I feel the seizures come more frequently.

When you fall into depression, you lock yourself up in your thoughts.

Like I told her [RA], I usually don't talk about it to other people because I am embarrassed.

I basically don't know anyone else who has the same thing I do [epilepsy]. Not in my country and not here. So, I would like to share with other patients the experience and how it feels.

It is great for people like us that have epilepsy since we have a lot of stress, anxiety, depression ... because I also don't like taking too many medicines, it makes me feel even sicker.

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**B. Feedback about UPLIFT**

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I really enjoyed both exercises ... by simply breathing that way you change your way of being at the moment.

It's good to meditate ... not think about stuff, clear my mind. It's like I forget everything

You do that at church when you go and meditate with God. You relax and think about your problems and ask God for help, it is very similar except you do it on your own.

Thank God it doesn't mention the word "epilepsy" because if it did, the tranquility would simply vanish!

Relaxation! The people who suffer from depression, this is something marvelous because it gives you tranquility.

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<sup>a</sup>PWE = people with epilepsy.