

Developing a Storytelling Study for African Americans with Hypertension:

A Study Protocol

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Abstract

Objective. Storytelling is an engaging approach for promoting health and wellness among individuals with health conditions including type 2 diabetes (TTDM), breast cancer, and hypertension. Storytelling interventions are an evidence-based approach that has been effective in promoting behavioral change such as increasing physical activity, medication adherence, and making dietary changes. The use of storytelling to convey health information and promote behavior change is associated with increased engagement in self-management particularly in communities of color. The primary objective of this paper was to describe our process for developing the storytelling study; specifically, recruitment, screening, selecting storytellers, and developing a study-specific interactive website. The secondary objective was to describe the approach for conducting the feasibility study and conduct a 6-week web-based storytelling study. **Methods.** Between 2017 to 2020, we developed a storytelling study for African Americans with hypertension. During that period we recruited participants from a Federally Qualified Health Center, a local church, and at community events. We selected storytellers to share their experiences managing hypertension and filmed 10 storytellers. Presently, a feasibility and pilot study are underway, the goal of the feasibility study is to ascertain feedback about the stories and the study website from African American adults with hypertension. We will also conduct a 6-week pilot study with 30 African American adults to see if conducting a storytelling study online would be an effective approach for promoting behavioral change. **Conclusions.** We successfully recruited and filmed 10 storytellers and produced 9 stories about living with and managing hypertension. The feedback we received from participants in the feasibility and pilot study will be useful as we refine the design of the study to determine the potential for a future randomized controlled trial (RCT).

Introduction

Narrative communication is defined as nonverbal and verbal communication that is arranged in a logic manner to generate a meaning.¹ Storytelling narratives typically portray cause-and-effect relationships that impact characters over a period. Previous studies have indicated that audiences find narratives easier to understand and more compelling than traditional forms of health communication.² Narratives provide specific examples from which an individual can extrapolate more general truths via inductive reasoning. Storytelling is particularly effective in communities

of color and in communities that have strong traditions of oral storytelling. Storytelling has been used to promote behavioral change, encourage self-efficacy, and break down resistance to health-related messages.³ Stories may encourage and motivate the participant to learn more or to take similar steps towards self-care as described within the stories. Stories elicit emotional responses and participants are able to empathize with the characters in the story, therefore, the participants may more easily remember the information contained in the story.⁴⁻⁷

Storytelling interventions are designed for promoting healthy lifestyles and delivering health information in the form of personal narratives from individuals with similar health conditions as well as social and cultural backgrounds. The stories convey health information in a way that goes beyond didactic teaching; it instead teaches the individual by allowing them to observe and connect with the actions taken by the storyteller.⁸ Storytelling interventions have demonstrated success in communities of color, and have been used to promote healthy behaviors such as dietary change, increased physical activity, and medication adherence for outcomes such as breast cancer, colorectal cancer, type 2 diabetes, and hypertension.^{5,9-12} Storytelling interventions are also an effective approach for health education and health promotion among individuals with limited health literacy, functional literacy, and those less likely to use technology to access health information.

Technology is an effective approach for delivering lifestyle and behavioral interventions. Web-based interventions are accessible using personal or public computers and mobile devices such as phones or tablets. A recent report from the Pew Institute indicated that approximately 95% of Americans own a cell phone and 77% are smart phone owners.¹³ The same report indicated that 45% of all Americans own a tablet (e.g., iPad, Galaxy Tablet, Nexus, or Kindle Fire). Due to the COVID-19 pandemic there has been a steady increase in the use of mobile technology, particularly among older adults. In 2021, over 90% of adults reported using the internet was essential and 40% reported using digital technology/internet in new ways due to the pandemic.¹⁴ Developing an intervention using an interactive video website may be an effective and engaging approach for delivering a behavioral health intervention, particularly in communities underrepresented and underrecruited for technology-based interventions, such as the African American community and individuals living in communities of low socioeconomic status. Using an interactive website may also be an effective approach for reaching individuals that are concerned about meeting in-person due to COVID-19 and those at increased risk of severe complications of COVID-19 like those managing chronic conditions (i.e., diabetes, hypertension).

The prevalence of controlled hypertension is low among all racial and ethnic groups, but is particularly low in the African American community.¹⁵ Approximately 20% of African Americans have controlled hypertension.¹⁶ African Americans also have the highest prevalence of hypertension in the United States, with 45% of African American men and 46% of African American women having the condition.¹⁷ Social and environmental factors—including access to care, family history, as well as psychosocial stressors—contribute to the increased prevalence of hypertension and uncontrolled hypertension, and are also associated with poorer health outcomes seen among African Americans with hypertension. Behavioral and lifestyle interventions designed to improve medication adherence, diet, and exercise among African Americans have demonstrated success in behavioral change,^{18,19} but African Americans still experience challenges in achieving controlled hypertension and long-term behavioral change. There is a need to design engaging, effective, and impactful evidence-based studies and interventions to

promote health and well-being among individuals with hypertension, and to make these studies available and accessible to African Americans living with and managing hypertension.

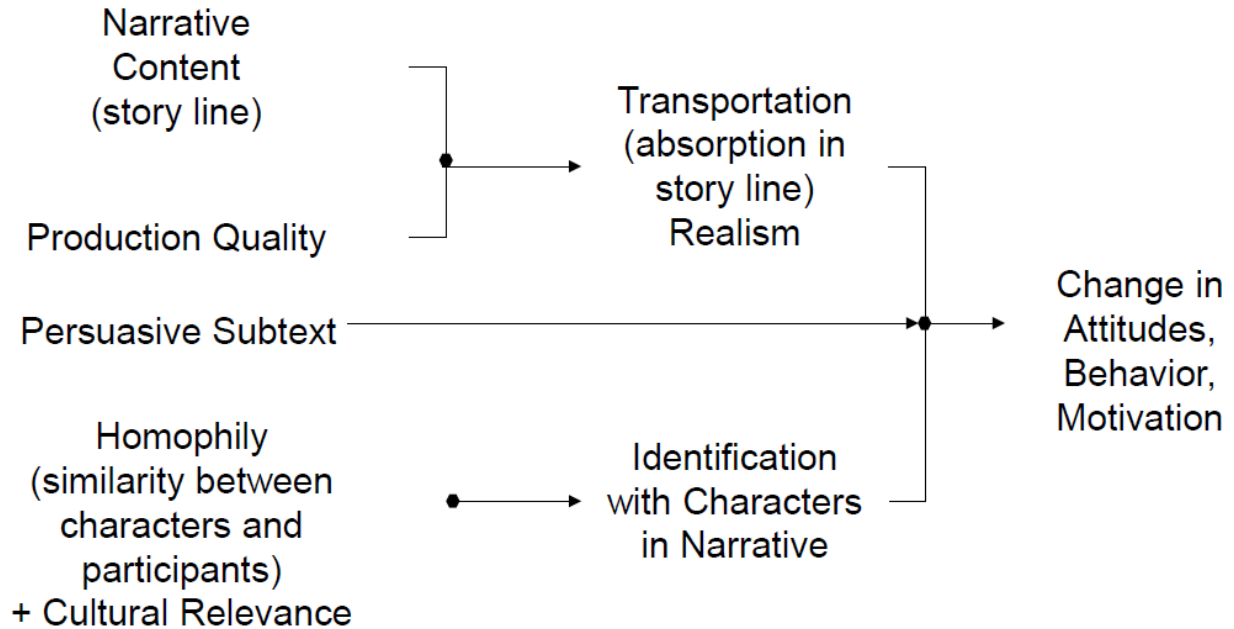
In response to this need, we developed the High Blood Pressure Stories (HBPSStories), a storytelling study, with the goal of promoting lifestyle and behavioral change, and reducing systolic and diastolic blood pressure. In this paper, we describe the two phases of this study: development and feasibility. The primary objectives of the development phase were to recruit African American adults with hypertension to describe their experiences living with and managing hypertension and to develop a study specific website as a platform for sharing the stories. The objectives of the feasibility study were to elicit feedback about the stories and website, and to conduct a 6-week pilot study.

Methods

Methodological Foundations

Our theoretical framework was developed based on an adapted version of the Slater Model of Narrative Communication Theory (see Figure 1).²⁰ This theory has been used to inform the design of storytelling interventions such as the Culturally Sensitive Intervention: Birmingham Study, which informed the design of our study.⁷ The advantage of a narrative communication (storytelling) approach is that it appeals to populations with limited health literacy and breaks down resistance to health messaging. The Slater Model of Narrative Communication Theory posits that four constructs contribute to changes in attitudes, behavior, and motivation. We will briefly summarize the theory which has been described in detail in similar studies.^{3,21} First, the combination of the narrative content (storyline) and production quality leads the viewer to become transported by the story and absorbed into the storyline.⁷ Second, the persuasive subtext provides an underlying concept of behavioral change that motivates the individual to make lifestyle changes. Third, homophily and cultural relevance (e.g., similarity between characters and participants) allow viewers to self-identify with the individual telling the story. Observing their similarities with the storyteller, the viewer is better able to connect to the story and picture themselves making the changes described. The content and relatability of the illustrations, combined with an engaging literacy level of appropriate text, may allow the reader to become absorbed into the story. Lastly, the subtle behavioral change subtext and visual similarities between the viewer and the characters in the story may contribute to greater engagement in the story and ultimately promote behavior change.

Figure 1. Adapted Version of the Narrative Communication Theory



Study Funding

The development phase of the HBPSStories study was funded by the Penn State Clinical and Translational Science Institute KL2 program. The program provided three years of funding to conduct this study; this phase of the study was completed in September of 2020. The feasibility phase of the HBPSStories study was funded by the University of Delaware COBRE Pilot Award, which provides one year of funding. The feasibility arm was awarded in December of 2021 and the study is ongoing.

Participating Sites

The development phase of the study was conducted at a Federally Qualified Health Center (FQHC) located in Harrisburg, PA, in a culturally and linguistically diverse area of the city. Many of the patients served by the FQHC were racial/ethnic minorities. The FQHC was an ideal location for recruitment, as over 5000 patients served by the clinic were receiving care and treatment for hypertension. The feasibility phase of the study is taking place at a Federally Qualified Health Center located in Wilmington, Delaware, which serves over 4,500 African Americans with hypertension.

Inclusion/Exclusion Criteria

The inclusion and exclusion criteria were the same for both the development and feasibility phases of the study. The inclusion criteria includes:

- 1) Diagnosis of hypertension;
- 2) Self-report being prescribed medication for the treatment of hypertension;
- 3) Age \geq 18 years; and
- 4) Self-report being African American or Black.

The exclusion criteria includes:

- 1) Mental status precluding ability to provide informed consent;
- 2) Pregnancy; and
- 3) Unable to speak or read English.

Development Phase

Aims of the Development Phase

The development phase consisted of two objectives: 1) storyteller recruitment and filming and 2) website development.

Storyteller Recruitment and Filming. Semi-structured interviews were conducted with 15 African American adults to identify storytellers. Storytellers discussed the successes and difficulties in managing hypertension. Ten participants were selected to be filmed as storytellers; interviews were 18–20-minute stories that were edited to 2–3-minute stories.

Website Development. During the website development phase, we collaborated with Hayman studios to create the website as a platform for delivering the stories and health education information obtained from the American Heart Association. The study website is www.HBPStories.com. The website was designed so that participants could access the password protected website from a mobile device such as a phone, tablet, or a personal computer. The website contained three sections: personal stories, health education, and a section to request more information.

Recruitment and Consent

Study participants were recruited from various sites in Central Pennsylvania, an FQHC, and at community-based events hosted by Derry Street Methodist Church. Physicians, nurses, and staff at the FQHC supported the study by identifying individuals that met the inclusion/exclusion criteria for the study and sharing the details of the study with the patients. The PI or a Research Assistant were on-site at the FQHC two days a week for on-site recruiting and conducting interviews. The FQHC hosted blood pressure screening and health education sessions twice a month during the Derry Street Methodist Church Food Pantry.

Individuals interested in participating in the study were scheduled for a 30-minute screening interview and a semi-structured interview to elicit stories. If the participants were unable to participate in the interview on the day of their visit to FQHC or at Derry Street Methodist Church, a phone interview was scheduled. Participants were consented during the phone interview or in-person. During the interview, the PI or study staff asked the participant questions from the Storytelling Project Script, to elicit their stories and to determine if the participant would be interested in engaging in the filming. The script encouraged storytellers to describe their experiences, particularly those related to the social determinants of health such as social support, accessing health care, transportation, and quality of care. Participants were encouraged to share their experiences, emotions, and concerns related to living with and managing hypertension. The script provided a framework for the storytellers to build upon. The PI reviewed the patient interviews and selected the participants who would have their stories filmed using the Storytelling Rating Form (Table 1). The selection criteria were based on the clarity of

the story, how engaging the storyteller was, and the impact of the information shared in the story. If the participant was selected to be a storyteller, the study manager contacted the participant to schedule the 1.5-2-hour filming session and to determine where the participant wanted to be filmed. Participants provided written consent before participating in the filming.

Questions from the Storytelling Filming Script

- Tell me the story of when you found out you had high blood pressure?
- Is there a person in your family or a friend that supports you in managing high blood pressure, please share a story of how they support you?
- After you found out you have high blood pressure, what did you do or where did you go to learn more about high blood pressure and your medication?
- What has been difficult or challenging about managing high blood pressure?
- What has made managing high blood pressure easier for you?
- Can you tell me a story about how you have made changes to manage high blood pressure?
- If you had a family member or friend that recently learned they had high blood pressure, what would you recommend they do?
- If they wanted more information about high blood pressure or places to get care, where would you recommend, they go?
- Please tell me why you decided to share your story about high blood pressure with others?

Table 1. Storytelling Rating Form

How well did the storyteller do in explaining things in a way that is easy to understand? Extremely Well Very Well Somewhat Poorly Very Poorly
How well do the stories get across the message of taking care of yourself? Extremely Well Very Well Somewhat Poorly Very Poorly
How well do stories provide specific examples of how to manage hypertension? Extremely Well Very Well Somewhat Poorly Very Poorly
How well do the stories reflect a positive attitude towards high blood pressure? Extremely Well Very Well

Somewhat Poorly Very Poorly
What was your overall impression of the videos? Extremely Well Very Well Somewhat Poorly Very Poorly

Study Design

Storyteller Recruitment and Filming. The storytellers engaged in a 18-20-minute interview to elicit personal narratives. The stories were focused on one or more of the social determinants of health (social support/social network, transportation, inability to afford medication, health literacy, housing instability, physical environment, locating healthy foods, and the patient-physician relationship). We recruited and interviewed 15 African Americans with hypertension. Participants reviewed a list of themes related to the social and behavioral determinants of health and used the themes as a guide when sharing their stories. Ten African Americans with hypertension were invited to share their stories of living with and managing hypertension. Ryan Hayman (videographer) filmed the storytellers in various locations in Harrisburg, Pennsylvania, including the FQHC, Broad Street Market, Midtown Bookstore, and the Susquehanna River Waterfront. Individuals selected for storytelling interviews received a \$20 gift card for participating in the study. Individuals selected as storytellers and those who completed the filming sessions received an additional \$40 gift card for a total of \$60 for completing both parts of the study.

Website Development. Dr. Cuffee and Hayman Studios website development team collaborated to develop the study logo and website. In July of 2019, the Hayman Website Development Team submitted a proposal for three mood boards providing options for the appearance of the website and three logos, which displayed a variety of colors, images, and layout options for the website. The PI selected the final logo and website design for the HBPSStories project. The website development team worked to create a mobile platform that would be accessible on a mobile device or a computer. For the health information section of the website, health information was obtained from the American Heart Association website and the American Heart Association of Central Pennsylvania. We selected six aspects of hypertension management (hypertension management, medication, healthy diet, active lifestyle, stress management, modifying behaviors) and provided brief educational information about each topic. The research team and PI collaborated with a peer-health coach, one of the storytelling participants, to review the materials and provide feedback on the topics that would be most helpful and informative to individuals managing hypertension. The peer-health coach had a background in health, physical activity, and promotion of physical wellness, and an interest in supporting projects that promoted her values and interest.

Ethics

The development phase of the study was reviewed and approved by the Penn State Institutional Review Board (IRB). The FQHC in Harrisburg did not have an independent IRB, but provided a letter of support with the IRB submission.

Feasibility Phase

Aims of the Feasibility Phase

The feasibility phase has two objectives: 1) To obtain feedback from individuals viewing stories and 2) to conduct a six-week web-based demonstration.

Story and Website Viewing.

During the *Story and Website Viewing* phase of the study, 30 African American men and women with hypertension watched the stories filmed during the development phase and provide feedback on the effectiveness and engagement with the stories. They also shared personal preferences about the design features of the study that would be most useful for a lifestyle and behavioral storytelling intervention. The participants were surveyed using Research Electric Data Capture (REDCap) after watching each story and provided feedback on engagement, satisfaction, impact of the storyteller, and the usefulness of the story.

Pilot Study.

Thirty African Americans with hypertension will be recruited from a FQHC in Wilmington, Delaware to participate in a 6-week storytelling study. The 30 participants in the pilot study will not be the same participants in the *Story and Website Viewing* phase of the study. Each week, participants will watch one story, review one module of health information, and then complete a short survey in REDCap about their experience watching the story and reviewing the materials. The participants will engage in two study visits, one at baseline and a second at 6-weeks. Blood pressure will be measured during each visit and data on self-reported diet, exercise, medication adherence, and other behavioral measures will also be collected.

Recruitment and Consent

For the *Story and Website Viewing* phase, we recruited participants from the FQHC in Wilmington, using flyers displayed at the University of Delaware, and at community events such as Newark Community Day. Participants were consented on-site for in-person visits and online using Adobe consent forms and using the signature function in HIPPA approved Zoom.

Study Design Feasibility Phase

Story and Website Viewing Phase.

During the baseline visit, the research team confirmed that potential participants met the inclusion/exclusion criteria, then had the study details explained and were consented for the study. Participants were scheduled for a one-hour study visit to view the stories and navigate the website. During the visit, self-reported demographic data including age, gender/gender-identity, income, and years of education were collected. All study data was collected in REDCap. Participants were instructed to watch the nine patient videos (each 2-3 minutes in length) and complete a short 3-5-minute REDCap survey after each video. The order of the survey completion in REDCAP was randomized to alternate the order in which participants watched the videos. After providing feedback on the individual stories, participants completed a 10-minute survey to gauge overall satisfaction with the stories, engagement, usefulness of the website, and potential uses for future studies. The feedback from the surveys will be used to rank which

stories were most informative and engaging, and to select the top six for the pilot study phase of the study. Participants were also invited to participate in a 10-minute exit interview to discuss their decision and motivation for participation and if they would recommend the study to family or friends. The study visit took 1-1.5 hours to complete, and participants received \$20 gift card upon completion of the surveys and an additional \$10 gift card for participating in the exit interview.

Pilot Study.

Thirty participants will engage in a 6-week online storytelling study and provide feedback on the effectiveness, engagement, and recommendations for improving the design of the study for future interventions. During the baseline visit, the participants blood pressure will be measured to confirm they meet the inclusion criteria, the study details will be explained, and a research team member will consent the participant. Each participant will be invited to participate in a one-hour visit training session for using and accessing the study website. Each week participants will be instructed to watch one of the 2-3-minute stories and engage with one module of health information on the website by logging into the website with participant-specific log in credentials. After reviewing the materials and viewing the weekly story, participants will complete a 5-minute survey in REDCap. The participants will also review the health materials from the American Heart Association on the website covering topics such as using an electronic pill bottle to manage medication, exercising at home, and cooking healthy meals. Participants will be expected to spend 30-minutes to an hour each week viewing the stories and study material, and will be reimbursed with a free blood pressure monitor and \$5 dollars each week for a total of \$30 upon completion of the study survey. The study includes a pre- and post-study survey to assess changes in diet, physical activity, and medication adherence. The exit survey will collect data about engagement with the study, reasons for not participating/dropping out, satisfaction with the study, and approaches for improving the study.

Ethics

The feasibility phase of the study was reviewed and approved by the University of Delaware IRB. The Federally Qualified Health Center in Wilmington does not have an independent IRB but has an internal review board that reviewed, provided feedback, and approval to conduct the study in conjunction with the Federally Qualified Health Center.

Planned Data Analysis

Qualitative data will be analyzed using NVIVO software. The study team will develop codes and conduct a thematic analysis, and two team members will analyze the data. For the *Stories and Website Viewing* phase we will apply a convergent mixed methods design. Specifically, the team will elicit common themes important for developing a behavioral storytelling intervention and descriptive statistics will be used to assess engagement of the storytellers and preferences for future interventions. The survey data and the quantitative data will be analyzed using STATA BE 17. We will collect quantitative data and conduct a baseline analysis of demographic variables using summary statistics, t-test, chi-square test and ANOVA. We will explore differences in engagement and preferences by gender, age, and income. For the pilot study we will analyze the data using qualitative research approaches. We will assess changes in blood pressure and self-reported changes in diet, physical activity, and medication adherence, using t-test, chi-square, and ANOVA, and adjust for age, gender, and literacy level.

Discussion

Storytelling is an underutilized yet potentially powerful approach for promoting lifestyle and behavioral change for African Americans with hypertension. Adapting the delivery of a storytelling studies using a web-based platform may be a more engaging and accessible approach. We anticipate that this study will provide greater insights into the influence of storytelling on promoting lifestyle changes. The six-week study will provide insights into the engagement and satisfaction with a web-based storytelling study, and the potential for conducting an RCT. The development and feasibility phases of this study will lay the foundation for a future storytelling intervention that combines web-based storytelling and community-based storytelling to determine the most effective approach for conducting a storytelling intervention.

Limitations and Strengths

The development and feasibility studies are limited in that both recruited from Federally Qualified Health Centers in urban areas. The study participants are all African Americans; therefore the findings may not be generalizable to other racial and ethnic groups. However, the goal of this study is to provide a foundation for a future intervention for African Americans with hypertension. The study has a small sample size, but the objective of this study is to conduct a pilot and feasibility study, in preparation for an intervention with a larger sample size. Participants were recruited from FQHCs and community-events focused on health; therefore, the study participants may be more engaged in their medical care and management of hypertension than individuals that do not have access to or receive regular care from a health center. A strength of our study is that our study design applies mixed methods data collection to glean greater insights from participants about the effectiveness, engagement, and satisfaction with a storytelling study. The feedback from these participants will be helpful in designing and informing the design of a future storytelling interventions.

Conclusions

Developing and conducting a storytelling intervention will be most effective if participants are engaged in the development of the study and are invited to provide feedback about the study design. For the present study, we elicited feedback on the stories, website, and participant recommendations for the design of a future intervention. It is our hope that this feedback will provide important insights for designing an intervention that will be effective in promoting lifestyle and behavioral change but is also tailored to the needs of potential study participants. Our study findings will provide guidance and recommendations that might be useful for other researchers and providers interested in developing or conducting storytelling interventions for hypertension.

Funding: Dr. Cuffee was supported, in part by Grant 5 UL1 TR002014 and 5 KL2 TR002015 from the National Center for Advancing Translational Sciences (NCATS).

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