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Adapting Effective Narrative-based HIV Prevention Interventions to Increase Minorities' Engagement in HIV/AIDS Services

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Abstract

Disparities related to barriers to care for HIV-positive and at-risk minorities continue to be a major public health problem. Adaptation of efficacious HIV prevention interventions for use as health communication innovations is a promising approach for increasing minorities' utilization of HIV health and ancillary services. Role model stories, a widely-used, HIV prevention strategy, employ culturally tailored narratives to depict experiences of an individual modeling health risk reduction behaviors. This paper describes the careful development of a contextually appropriate role model story focused on increasing minorities' engagement in HIV/AIDS health and related services. Findings from interviews with community members and focus groups with HIV-positive minorities indicated several barriers and facilitators related to engagement in HIV healthcare and disease management (e.g., patient/provider relationships) and guided the development of role model story narratives.

INTRODUCTION

Eradication of health disparities is a major public health priority in the United States (National Institutes of Health, 2002; U.S. Department of Health and Human Services [USDHHS], 2000). However, availability and access to health care remains inconsistent across communities (e.g., Andersen et al., 2000; Heisler, Rust, Pattillo, & DuBois, 2005). Despite advances within the medical care system, healthcare facility infrastructure improvements, expansion of needed community services, and medications to improve health and extend life, the divide between the "health care haves and have nots" remains (Hurley, Hoangmai, & Claxton, 2005). As a critical strategy for reducing disparities related to barriers to care in an era of exorbitant health care costs, national priorities have been established with goals calling for health communication innovations to facilitate minorities' engagement in health care and ancillary services (USDHHS, 2000, 2003). This article describes the development of a health communication innovation to increase African-Americans' engagement in HIV/AIDS health and related services.

Progress on health communication goals is critically needed in the area of HIV/AIDS where health disparities are increasingly prevalent among minorities (McDavid, Li, & Lee, 2006; RAND Health, 2006). Currently, there is a substantial literature on effective primary prevention interventions to reduce risk of HIV infection in minority communities (e.g., Centers for Disease Control and Prevention [CDC], 1999, revised 2001; Solomon, Card, &

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Malow, 2006). Some of these HIV primary prevention interventions have even incorporated health communication components to address safer sex communication, health literacy, and media advocacy (e.g., CDC AIDS Community Demonstration Projects [ACDP] Research Group, 1999; Lauby, Smith, Stark, Person, & Adams, 2000), and many have been designed with core elements that are culturally and linguistically grounded for community-based applications (e.g., Downing et al., 1999; Kalichman & Coley, 1995; Kalichman, Kelly, Hunter, Murphy, & Tyler, 1993; Terry et al., 1999). Furthermore, there is increasing literature on adapting these HIV primary prevention interventions for new community settings and targeted minority populations (e.g., Eke, Neumann, Wilkes, & Jones, 2006; Gandelman, DeSantis, & Rietmeijer, 2006; McKleroy et al., 2006; Solomon, Card, & Malow, 2006). However, little research has been focused on adapting these primary prevention interventions to target new behaviors associated with HIV treatment and survivorship, such as increasing minorities' engagement in HIV health care and supportive services.

Adapting prevention interventions to promote minority use of HIV services may be especially important for African Americans as rates of HIV infection have continued to be disproportionately higher in this population (CDC, 2005). For instance, African Americans represent only 13% of the population in the U.S., yet they account for 50% of new HIV infections (Prejean, Satcher, Durant, Hu, & Lee, 2006). Additionally, HIV/AIDS is among the top ten leading causes of death for African Americans nationwide, and African Americans who died from HIV did so sooner than non-Hispanic Whites (Anderson & Smith, 2005). Despite their overrepresentation, research indicates that African Americans, as compared to Whites, are more likely to have delayed HIV treatment and are significantly less likely to receive effective HIV treatment and other needed health services (Turner et al., 2000; Wong et al., 2004).

A myriad of overlapping personal, social, and environmental factors are associated with HIV/AIDS disparities in health care and related outcomes for many African Americans including substance use, unemployment, untreated mental health problems, delayed HIV testing, and poor HIV medication adherence; the high cost of health insurance, health services, and medication; and inadequate transportation, housing, and social support (e.g., Culhane, Gollub, Kuhn, & Shpaner, 2001; Cunningham et al., 2005; Gebo et al., 2005; Joyce, Chan, Orlando, & Burnam, 2005; Kenagy et al., 2003; Shlay et al., 1996; Smith et al., 2000; Stewart, Cianfrini, & Walker, 2005; Turner et al., 2000). As African Americans continue to incur disproportionate HIV infection rates, further research on connecting minorities to care is needed (Molitor et al., 2006). Development of health communication innovations to engage African Americans in care – from prevention to treatment -- may be a promising approach for reducing HIV morbidity and mortality. To expedite development of such health communication innovations, potentially suitable primary HIV prevention strategies need to be identified and adapted to target health care and support services utilization for minorities.

Identification of an adaptable HIV prevention intervention

An HIV prevention strategy that may be particularly appropriate for adaptation in the development of health communication interventions is the use of role model stories (e.g., CDC ACDP Research Group, 1999; Lauby et al., 2000). Primarily based on social learning-cognitive theory (Bandura, 1986), role model stories combine experiences of a “model” individual with targeted protective behaviors (e.g., condom use) in a narrative format that incorporates cultural values, language, and local relevancy for targeted communities (Corby, Enguidanos, & Kay, 1996; Corby, Enguidanos, & Padilla, 1997). Unlike statistical or didactic health communication, role model stories share information in a non-threatening manner by fostering identification with story characters and experiences, engaging recipients

with storyline messages, appealing to personal values and interests, reducing counterarguments against key messages, and improving information retention (Hinyard & Kreuter, 2006).

Effective HIV prevention intervention studies that have used role model stories include the AIDS Community Demonstration Project (ACDP; CDC ACDP Research Group, 1999), the Woman and Infants Project (Lauby et al., 2000; Terry et al., 1999), and the Perinatal HIV Reduction and Education Demonstration Activities Project (Downing et al., 1999). In these studies, interviews were conducted with African American community members (e.g., those at risk, outreach workers) to understand challenges, motivators, locality references, and linguistic nuances related to practicing HIV protective behaviors. Interview findings were crafted into brief stories that consisted of the role model moving from ambivalence about protection to actively engaging in target protective behaviors, such as using condoms. Essential role model storyline elements included use of narrative on contextual background, personal and environmental challenges and barriers, behavioral targets, attitudinal and behavioral changes, and reinforcement of the achieved target behavior by suggesting the role model's benefits or personal satisfaction with the outcomes (e.g., Corby et al., 1996).

Stories were distributed by near-peers (e.g., peer counselors, outreach workers, health providers) and through small media outlets (e.g., flyers, cards, newsletters) to community members. Also, other items, such as condom key chains, were offered to increase the likelihood of participants engaging in protective behaviors. These strategies were found to increase condom use by 73.6% in intervention cities. Increased intervention exposure was correlated with increased condom carrying rates. This effective HIV prevention approach is now known as "Community Promise" and is packaged for implementation with organizations that provide services to at-risk populations (CDC, 2001).

Despite the successful use of role model stories in HIV primary prevention interventions (e.g., Downing et al., 1999; Jamner, Wolitski, & Corby, 1997; Terry et al., 1999; van Empelen, Kok, Schaalma, & Bartholomew, 2003), there is little research on using role model stories to reduce barriers to care and increase utilization of available HIV/AIDS treatment and support services. We posit that the use of role model stories as a core component of health communication interventions may be beneficial for linking African Americans to HIV care and related services. We suggest several reasons (e.g., storytelling genre, adaptable and culturally-tailored formats, information delivery through near-peers, enhanced health literacy) for this consideration.

First, role model stories are akin to the storytelling heritage in the African American culture where preachers, dancers, rappers and others adapt oral stories "to reach and teach the hearts and minds of listeners in inimitable ways" (Goss & Barnes, 1989, p. 9). Storytelling can be a non-threatening way to disseminate health information in African American community settings (Banks-Wallace, 2002; Leoutsakas, 1996; ORC Macro, 2004), such as in barbershops, churches, and community groups. Additional support comes from narrative theory which posits that humans share knowledge and experience through their ability to communicate with each other through storytelling (e.g., Fisher, 1987).

Second, role model stories can be adapted to various formats (e.g., print media, testimonials) to stimulate the curiosity and interest of intended audiences and to overcome challenges in and resistance to seeking protective health screening and treatment (Kreuter et al., 2007), particularly when a scarcity of HIV services exist. This benefit could be especially important, as decreasing budgets and availability of HIV services, increasing health care costs, and medical mistrust negatively impact access to care for many minorities. Also, role model stories can be formatted with images of African Americans as role models and can

incorporate culturally appropriate language, customs, and environmental elements tailored to the targeted reader's personal experiences and characteristics of their daily lives for increased source credibility (Bailey, Erwin, & Belin, 2000; Kreuter & McClure, 2004).

Third, African American community members and other near-peers can serve as channels of communication in various settings for distribution of role model stories to further increase receptivity of the health messages. Finally, HIV+ individuals can be overwhelmed by the volume of HIV information received, especially at diagnosis, which is often in formats requiring advanced reading and comprehension skills (Kalichman & Rompa, 2000). Use of role model stories may provide a stimulating way to deliver healthcare and service information in a user-friendly, comprehensible, culturally-relevant, and low-cost manner.

We describe a process for developing a role model story-based health communication tool to increase minorities' utilization of HIV services for disease management. Similar to the role model story-based HIV prevention intervention development process (e.g., Corby, Enguidanos, & Kay, 1996), we first gathered information on the HIV/AIDS contextual community background. We then collected information on available HIV services and challenges and facilitators related to disease management and service utilization as described by HIV service providers and HIV+ individuals. The collected information was used to: a) identify role model story thematic issues, storyline elements, and characterizations; b) develop the role model stories; and c) create a user-friendly role model story packaging format.

METHOD

Contextual Background

In the Kansas City (KC) metro area, the HIV/AIDS epidemiological profile suggests a trend similar to national statistics for infection rates among African Americans. African Americans comprised 14.1% of the KC region population in 2004, yet they accounted for 36.3% of newly diagnosed HIV cases (MO Department of Health and Senior Services, 2005). KC African Americans face the greatest risk of HIV infection, with incidence rates 2.8 times higher for males and 17.8 times higher for females than that of their White counterparts. In fact, 69% of the women infected in the KC metro area in 2005 were African American (KC Health Department, 2006). Also consistent with national trends, KC area HIV+ African Americans on average progressed to an AIDS diagnosis more rapidly than Whites. A contributing factor to this trend is that nearly 30% of KC HIV+ African Americans are *not* receiving primary medical care (KC Health Department, 2005). A local needs assessment found that HIV+ minority consumers' lack of access to emergency financial assistance, housing, and transportation were the top three barriers to care (Urban Mission Program, 2005). Other barriers to care included: language/communication challenges, inability to pay insurance premiums, case management system breakdowns, and cultural issues.

Semi-structured interviews

Participants—Using directories of local service organizations, we identified twelve key stakeholders in the HIV/AIDS community (e.g., healthcare providers, community advocates, AIDS service organization (ASO) staff) and asked them to participate in an interview. Our goals for selecting these participants were: a) to understand the contextual background of HIV/AIDS in KC, available HIV services, and minorities' challenges in using HIV health and supportive services; and b) to develop relationships with stakeholders who could provide channels for dissemination of a role model story-based intervention. After we obtained informed consent, twelve community stakeholders (4 males, 8 females) agreed to

participate in an interview, each lasting about 1½ hours. All aspects of this study were reviewed and approved by University of Missouri-Kansas City Institutional Review Board.

Interview procedures and topics—Our semi-structured interview questions with key stakeholders focused on their AIDS service organization's: HIV prevention, treatment, and social services provided; demographics of patients/clientele; steps required of patients to access services; funding for services provided; gaps in services; and challenges in providing/seeking their services. Interviews lasted about 1 – 1½ hours.

Data analysis—Two of the studies' researchers transcribed and coded the interviews. We used Glaser & Strauss' (1967) ground theory approach to develop coding categories. We first "open-coded" the transcriptions by identifying key words, full comments, and descriptions of behaviors related to engagement in care and disease management (e.g., Bender & Ewbank, 1994; Krueger, 1998). We then grouped initial coding into thematic categories (e.g., seeking HIV information, using support systems), and a code map with thematic descriptive elements was developed to allow us to recode and categorize the transcription text.

Focus group discussions

Participants—We conducted focus groups with HIV+ persons who: a) accessed HIV health services at least twice a year, b) were on a steady antiretroviral regimen for nine months or longer, c) self-reported adherence > 90%, and d) had a stable viral load, and e) had overcome barriers to care. We recruited these participants from two large infectious disease clinics in the urban Kansas City area. After we obtained informed consent, 18 individuals agreed to participate in a focus group discussion and to complete a brief survey on HIV disease management. Participants consisted of 10 African Americans (7 females, 3 males), 5 Caucasians (3 females, 2 males) and 3 Hispanic males. Focus group results below are reported for African American and Hispanic respondents. The mean age for minority participants was 43 years old (27-58 range). Almost all (92%) had a high school diploma, GED, or higher education.

Focus group procedures and topics—We conducted four focus groups in conference rooms within local ASOs and within the authors' university department, which were all convenient to midtown Kansas City, MO and accessible by public transportation. The focus group discussion consisted of topics on barriers, facilitators, motivators and strategies for managing their HIV disease and accessing supportive services. Focus group participants received monetary incentives to cover transportation costs, and a meal was served during the focus group. The focus group discussions lasted about 1½ hours with the same facilitators (first and fourth authors of this article) for each group.

Data analysis—Analysis procedures were conducted in the same manner as those described for the semi-structured interviews.

Survey on HIV disease management

Participants—Participants who completed the HIV disease management survey are the same as those described for focus groups.

Survey procedures and questions—Prior to the start of each focus group discussion, we asked participants to complete a 5-minute survey, which included questions on to what degree of barriers and facilitators impacted their disease management. Facilitator items (e.g., "having a provider location that is easy to get to") and barrier items (e.g., "no housing or own place to stay") were ranked on a scale of 0 to 3 (with "0"=not at all and "3"=a great

deal). The survey also asked participants to indicate the types of HIV ancillary services they had used.

Data analysis—We used requisite univariate analyses, such as means and percentages, to report data on demographics, barriers and facilitators to disease management, and use of ancillary services.

RESULTS

Semi-structured interviews

Interviews with twelve community stakeholders' generated several challenges for minorities, particularly African Americans, in accessing HIV-related services. We categorized these challenges under three broad themes related to the continuum of HIV care. These themes and their descriptive aspects [shown in brackets] were: a) HIV screening [HIV testing, linkage to care], b) HIV medical treatment [maintenance of appointments, patient-provider interactions, comorbidities, funding and system issues], and c) HIV survivorship [supportive services, stigma].

HIV screening—Respondents expressed a need to improve strategies for promoting free, rapid HIV testing and counseling services in community settings (e.g., clubs, health fairs, and clinics) and having community peers participate in providing these services to increase the likelihood of early diagnosis, as stated in this comment:

“We have tried community outreach to increase testing through beauty shops and barbershops and drop-in shelters. But our biggest obstacle is getting the information delivered through a trusted peer.”

Respondents noted that many clients were not quickly linked to care after testing positive for HIV and that ASOs needed to figure out creative ways to get their clients into care, as suggested by this comment:

“We have got to move from early intervention, or what used to be called “outreach,” to getting people into care! Getting [high risk populations] quickly into care and be able to show that.”

HIV treatment—Respondents stated that once clients had been linked to treatment, despite the challenges (missed medical appointments, mistrust of providers, poor patient-provider communication, and limited transportation), it was critical to keep them in care as stated here:

“Providers' must make keeping patients in the system a priority!”

Respondents commented on the need for ongoing diagnostic and treatment services for comorbidities, such as mental health and substance abuse disorders, and the lack of funding to address these issues. They also commented on the challenges of accessing care when clients had to deal with state and federal budgets cuts of available HIV services and increasing HIV medical care costs -- which made seeking HIV services an extremely effortful task. Funding cuts forced their organizations to reduce availability of critical services or make eligibility requirements stricter. Also, their organizations experienced frequent staff turnover, an ongoing need to train new employees on available HIV services, and burdensome paperwork and procedures, which further hindered provision of care and access to care as these comments suggest:

“We have structured programs, and the process can be difficult for patients to maneuver without patient commitment. There are challenges to design programs to adapt to all of the different client needs in different areas. This is without enough case managers and with limited funding.”

“For our nurses and med students, we try to keep them informed of available services in the community... Sometimes this can be daunting, because of the turnover of staff and different services available.”

HIV survivorship—Respondents commented on the fact that many of their patients were living longer with HIV due to the advent of new HIV medications. However, this survivorship brought increased need for transitional and long term housing and employment assistance for many minority HIV+ clients to maintain engagement in care. They stated that many of their African American clients experienced loss of employment and/or lived in marginal housing due to HIV-related illness. Many times their patients’ essential needs for survival (e.g. food, shelter) surpassed the immediacy of accessing needed health services as stated here:

“We have to deal with why are people not in care. There are social and economic issues to accessing care. Some of the biggest are money for food and shelter and funding to assist them.”

They also noted that because of stigmas associated with HIV, some HIV+ African Americans chose not to seek HIV care for their disease.

Survey on HIV disease management

Among all minority HIV+ participants, 92% had used at least one HIV ancillary services (i.e., case management). Other services received included assistance with housing (46%), food (23%), and finances (8%). Survey findings with HIV+ minority participants indicated several facilitators for successfully managing their HIV disease. Most frequently noted facilitators included: a good relationship with their providers (3.0), providers that cared about them (3.0), a good understanding of how to take their medication (3.0), believing their HIV medication kept them healthy (3.0), and keeping healthcare appointments (2.9). This study’s respondents did not indicate that barriers greatly impacted their disease management and access to services. Barriers noted most frequently included: people with negative attitudes (2.0), chaotic life conditions (1.3), side effects (1.1), alcohol or drugs (1.0), and unaffordable medications (0.85) and not enough money for daily needs (0.85).

Focus groups

In the focus group discussions, four primary thematic categories related to disease management and engagement in health and ancillary services emerged. These themes and dimensions that describe their meaning [in brackets] consisted of: a) maintaining supportive medical care [appointments kept and lab work done on a regular basis; valued patient-provider communication and relationships; informed providers], b) seeking out HIV information for personal empowerment [gathering HIV information from multiple sources, advocating for self/others], c) using support systems [supportive people, groups, and strategies], and d) having a positive outlook on life [dealing with HIV disease-related challenges, hope in living]. Samples of participants’ comments on these themes are provided below.

Maintaining supportive medical care—All of the participants discussed the importance of having a caring, informed provider who worked *with* them in determining

best methods for disease management and whom they met with on a regular basis. They noted that they needed to be able to trust and have a good relationship and communicate with their physician, which was important to maintaining their engagement in care. Participants' comments related to desiring good provider communication and relationships included:

“The first doctor I had, we didn't converse as much as with my second doctor. I didn't have that one-on-one relationship with my first doctor. She wasn't as informative as much as my doctor is now.”

“Find a provider that you trust that's going to help you make the right decisions. But don't depend on them to make the decisions for you. Be knowledgeable enough to make healthy choices for yourself.”

“[My doctor] told me you need to take it, you need to take it on time and that was pretty much it. He didn't explain any of what he said.”

Participants sought to get their blood drawn on a routine basis in order to monitor their CD4 count and viral load. This information reinforced their commitment to be responsible and maintain control of their health as stated in the following comment:

“[When I get my lab work done] I'm contributing to the fact that my levels are remaining undetectable, you know then I am in control of my disease. I've always been a person who always likes to be in control.”

Seeking out HIV information for personal empowerment—Almost all participants sought information on their HIV medications, side effects, and HIV disease in general. Many learned more about HIV and disease management from their providers and also sought out information from HIV + friends and support group members. Most participants accessed HIV information on the internet and mentioned co-learning about disease management with providers. Educating themselves on HIV helped them to make informed health decisions, advocate for themselves and others, and stay in control of their care. Comments related to seeking information and personal empowerment included:

“Knowledge is always important. I mean I really need to know. And the more I know, the more that I feel as though I'm making good choices or that I have a choice. Because without the knowledge, you're just going on what somebody says or you just accept it. But if I have the knowledge I'm able to dispel ignorance, even if it's nothing but my own.”

“I made a promise to myself that I was going to be involved in my health care. I do know that advocacy for some individuals is rather difficult and that's where [peer educators] can step in.”

Using supportive systems—All of the participants mentioned seeking out supportive significant others, support groups, and spiritual supports, such as prayer and engaging in church activities. One participant's comments on why she sought out a support group included:

“I think a women's support group was good for me, because I can relate to the other women. We're going through the same things and we can talk about issues.”

Having a positive outlook on life—All of the participants were very hopeful about their futures and had a strong desire to stay healthy. Many had overcome issues, such as finding a physician they could trust, coping with HIV medication side effects, disclosing their disease

to others, and seeking employment. They had developed a “new normal” for living and a strong desire to live as stated in the following comment:

“I’m passionate about life and the fact that I am alive.”

Additional focus group participant comments are shown in Table 1.

ROLE MODEL STORY MESSAGE DEVELOPMENT

Thematic issues and storyline elements

Information gathered from the community partners and HIV+ individuals provided the thematic issues that guided the message development for the role model stories. Table 1 outlines the process by which role model story messages were developed based on two identified thematic issues derived from interviews and focus groups — maintenance of routine medical care and medication adherence. Specific comments were aligned with particular storyline elements (e.g., personal challenges, attitude/behavior change) to serve as core narrative text with attention to participants’ reported behaviors, beliefs, personal stories, and anecdotes related to managing their disease and engagement in HIV services. Also, as much as possible, the role model story text maintained participants’ verbatim comments for cultural appropriateness, comprehensibility, and “referential involvement” where the targeted audience relates the messages to their own personal experience (Geary et al., 2006).

To further elucidate how storyline elements come together in a final product, Figure 1 depicts an African American female who struggles with keeping her doctor’s appointments and taking her HIV medications. The role model story depicts how she moves beyond ambivalence and : a) makes a commitment to keep doctor appointments and take medications, b) develops trust in her doctor, c) gains support, and d) enjoys some of favorite pastimes due to her improved health. Included in her story are successful strategies and beneficial outcomes from seeking HIV services.

Community member feedback

ASO staff and HIV+ African Americans reviewed the draft and final role model story. They provided feedback on accuracy of information, readability, cultural appropriateness, and future applications within their respective organizations. Some of the suggested end-products formats that could work well with their staff and clientele included: an audio format where role model stories could be told by African American storytellers, computer kiosks with story selections based on individual need (e.g., housing or food assistance), and cards printed with the storyline. They also suggested including ASOs’ contact information, primary bus routes to get to the ASO locations, and a bulleted listing of their services. Community members noted the utility of using role model stories to teach new employees about available local services and barriers to care that their clients could potentially encounter. Additionally, they provided unsolicited storyline scenarios for the creation of more role model stories based on their experiences with clients. For example, an ASO provider suggested developing a role model story on disclosure of HIV status with significant others. In her experience, patients who did not disclose their HIV disease were more likely to miss medical appointments and skip taking medications, particularly if these activities put them at risk of being “outed” with family and friends.

Role model story end-product

Based on feedback from community members, we revised the role model stories and developed the end-product. We used medium-sized cardstock (5 ½ × 8 inch) to increase

durability and to keep printing costs low. Similar to the layout of role model stories used in other studies, the cards depicted the short role model story on one side along with an African American person representing the storyline role model. Layout of the stories included an easy-to-read font, borders, and a pictorial of the representative model. Information about the particular ASO was highlighted on the back of each role model story. The back of the cards also included primary bus routes and their major street connections, contact information, services offered, and hours of operation. End-product role model story had a Flesch—Kincaid Grade Level Index of 5.7, indicating a reading level between the 5th and 6th grade (Flesch, 1948).

CONCLUSION

As HIV infection rates continue to disproportionately affect communities of color and inequities in healthcare resources continue to exist, health communication strategies that empower individuals from these communities to actively seek HIV health and ancillary services are needed. The current study focused on the development of a role model story-based health communication innovation to increase linkage to HIV care for minorities. Telling stories is a central form of communication that can be used to share experiences, explore new ideas, and share information in an engaging way. In particular, storytelling continues to be a rich tradition in the African American community in various forms of communication from sermons spreading the word of hope to rap music detailing societal injustices. Use of stories as an intervention strategy -- with culturally-appropriate empowering narrative, a focus on key behavior change elements (e.g., attitude/behavior change, reinforcement of targeted behaviors), and appropriate channels of dissemination -- may prove to be a promising health communication tool in addressing HIV health disparities with communities of color.

The scope and funding of the present inquiry aimed to explore the appropriateness of adapting a role model story development process used for effective HIV primary prevention interventions to a communication innovation for increasing health seeking behaviors. However, the current study is limited in its ability to fully explore the effectiveness of role model stories, and future studies on role model story effectiveness with diverse populations are needed. As interest in use of narrative communication strategies for the purpose of promoting health seeking behaviors continues to grow in academic and community settings (e.g., Kreuter et al., 2007), several implications for research and practice exist.

First, future research is needed on examining role model stories as a stand-alone intervention and in combination with non-narrative health communication tools to determine its effectiveness in increasing health seeking behaviors. Similar to studies of role model story-based HIV primary prevention interventions, it is critical to assess the efficacy of role model stories using appropriate incentives and reinforcers, such as transportation or meal vouchers, and through selected dissemination channels. Also, future research is needed to understand the differential impact of potential role model story factors -- such as the storyline and format design, “model” characterization, and emotive and persuasive elements -- that may influence health service seeking behaviors.

Second, consideration should be given to fully including representative community partners in the research process. By using community-based participatory research practices (Isreal, Eng, Schultz, & Parker, 2005), ASO staff, HIV+ and affected African Americans, and other relevant community members (e.g., storytellers, graphic designers) could serve as partners in developing, implementing, and evaluating role model story-based interventions. Using a participatory research approach, HIV+ persons and affected others could contribute to the ongoing creation and collection of culturally-appropriate and socially-validated role model

story end-products and the research methods used. They could assist in “quality control” by ensuring stories are appropriately tailored for targeted segments of a specific community (e.g., pregnant women, men who have sex with men). They could also identify emerging issues related to seeking HIV services while providing personal anecdotes on overcoming challenges to seeking services. While the relative ease and low-cost of producing role model stories is an obvious advantage, care must be taken to ensure that the content does not alienate, offend, or provide inaccurate information to clients. Community partnerships could work together to provide such oversight on role model story appropriateness, accuracy, and attention to storyline elements.

Third, more work is needed to establish effective role model story dissemination strategies. ASOs will likely prove to be suitable sites for dissemination. For example, computer stations in ASO waiting rooms could offer access to personally tailored RMS by asking clients to provide personal information (e.g., ethnicity, gender, sexual orientation) and topics of interest (e.g., HIV testing, medication adherence, housing, transportation). The role model story could then link clients to local services and transportation information. ASOs could also work with theatre students or local storytellers to produce entertainment-based role model story programs that are infused with lively dialogue and rich, local dialects for use in their outreach programs.

Fourth, effective community collaborative partnerships could also enhance the sustainability of role model story-based initiatives by building on community partners’ collective experiences and resources and establishing cost sharing strategies (e.g., printing, institutionalization of dissemination practices, joint grantwriting). By working together on role model story-based interventions, representatives of minority communities and healthcare institutions could begin to foster co-learning and mutual respect. Finally, these collaborative partnerships could begin to explore to what degree role model stories may assist in increasing personal and community empowerment for taking action in advocating for health care system changes and in increasing access for all.

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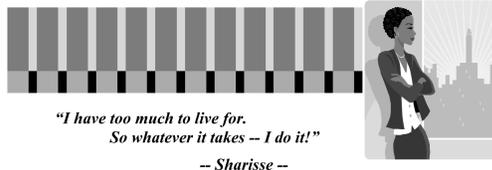
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I've always been the kind of person who likes to be in control. My kids tell me I can't be the boss of everything. I know this, but it doesn't stop me from trying.

Like after I started taking my HIV medications, I had all kinds of side effects. I mean the meds were really cutting my stomach up. So I started thinking about not taking my meds just so I could feel better. I started missing doctor appointments too. See, I was really bummed out about having HIV. Then one day I started having dizzy spells, and I got a hold of my doctor quick!

I made sure I kept this doctor's appointment. And I'm glad I did. My doctor was concerned about my health and my life. We talked about other meds and things I could do to help with the side effects. Now I call or e-mail my doctor anytime I have questions. While I was at the clinic I talked with a caseworker. She got me into a women's HIV support group and hooked me up with other HIV services in KC.

On the way home, I looked at the Plaza fountains and the people playing in the park. I thought about my kids, my family, and all I have to live for. I made up my mind that I wanted to live. I told myself that I will take my meds on time, every time.

Now I keep all of my doctor appointments -- no matter what! And I feel much better. My doctor and I figured out a way for me to take my meds that works for me. I feel more comfortable with my doctor now. And I check things out for myself. I read and go online to stay educated about HIV. And even though I hate the needles, I have my blood work done regularly. I keep track of my CD4 and viral load counts. I like knowing that I'm doing okay.

And my HIV support group is good for me because I can relate to the other women. I am working again and doing things I like to do like going to church and playing with my kids. See, I'm passionate about life now and the fact that I am alive. I know I can't be in control of everything. But I like the fact that I can be in control of how I live with this disease.



FIGURE 1.
Role Model Story on Maintaining Clinic Appointments and Taking HIV Medication

TABLE 1

RMS Development Based on Thematic Issues: Maintenance of Routine Medical Care and Medication Adherence

Thematic Issue	Participants' Comments	■Example Storyline Elements	Related RMS narrative
Patient provider relationship -- Communication	"Because of the relationship that [my second doctor] and I have with each other, it brought me to want to learn how to live with [HIV] and not die from it. And that was something she expressed to me and with her saying that to me -- life as oppose to death. It immediately triggered something totally different in me. It's like, wow, <u>I can live with this.</u> "	Attitude/behavioral change: ■ Improved perspective on living with HIV based on positive communication with a newly selected doctor	"My doctor was concerned about my health and my life." "...I can be in control of how I live with this disease."
Patient provider relationship -- Shared responsibility and learning	"I take my meds because I want to live. And I'm like, no I really don't want to die. I mean, so whatever it takes... seeing my doctor when I'm supposed to, getting my blood drawn when I really don't want to. It's once every three months. I keep all of my doctor's appointments. In fact, I have a mammogram and ultrasound tomorrow." "I'll check myself, so <u>I'll go online.</u> " "It's like okay whatever we decide, <u>we gonna work together to educate me.</u> "	Attitude/behavioral change: ■ Maintenance of doctor and other health appointments	"I keep all of my doctor's appointments." "And now I'll check things out for myself. I'll read and go online to make sure I educate myself about what's going with the disease and my body." "So whatever it takes... I do it."
Patient provider relationship -- Trust	"[My doctor] answers my questions. And if she doesn't know, <u>we'll figure it out together.</u> <u>And I really feel comfortable in her care.</u> "	Reinforcement of behavior change: ■ Positive relationship with doctor	"My doctor and I figured out a way for me to take my meds that works for me."
Lab services	"And by the way, my counts. My CD4 was 112 when I first started. It's about 400 now. I do <u>keep track of my counts.</u> I be wanting to know, because it was really bad when I first found out, so." "It reinforces it, that I'm doing it okay. When I go have my blood work done and my doctor says everything's fine. Even though <u>I hate the needles.</u> But to hear my doctor say, "Your levels are still undetectable."	Reinforcement of positive/protective behaviors: ■ Seeking lab services (e.g., blood drawn to assess CD4 count and viral load), monitoring health status based on results, and affirming the value of lab information and pill taking behavior	"I hate the needles, but I have my blood work done regularly. And I keep track of my CD4 and viral load counts. I want to know that I'm doing okay."
Medication side effects	"So [the medicine] was just cutting my stomach up." "When I first started taking medications... it affected my stomach, my stomach was upset. So <u>I'm thinking dang my stomach is messed up.</u> "	Personal/environmental challenges: ■ Negative side effects from taking HIV medication.	"I was like, dang these meds are cutting my stomach up."
Support groups	"I think <u>a support group was good for me,</u> a women's support group. Because <u>I can relate to the other women.</u> We're going through the same thing and we can talk about issues."	Attitude/behavioral change: ■ Seeking support and disclosure Reinforcement of behavior change: ■ Camaraderie and validation	"And my support group is good for me, because I can relate to the other women."

Thematic Issue	Participants' Comments	■Example Storyline Elements	Related RMS narrative
Future perspective	<p>“<u>There is too much to live for.</u>”</p> <p>“I determined that <u>I wanted to live.</u> So I was going to do all that I could do within my power.”</p>	<p>Attitude/behavioral change:</p> <ul style="list-style-type: none"> ■ Positive outlook on life and living with HIV <p>Contextual background:</p> <ul style="list-style-type: none"> ■ Desire to be in control 	<p>“I thought about my family and all I have to live for.”</p> <p>“I made up my mind that I wanted to live.”</p>