

ORIGINAL ARTICLE

**The Brief Disclosure Intervention (BDI):
Facilitating African Americans' Disclosure
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HIV+ African Americans face many challenges that may be addressed by increased social support. This manuscript presents the Brief Disclosure Intervention and explores strategies to tailor the intervention to facilitate disclosure, increase social support, and ameliorate health disparities among HIV+ African Americans. The disclosure decision-making model served as the theoretical framework. HIV+ African Americans (N = 43) in New Jersey participated in structured interviews at 2 time points and half received the intervention. The intervention group reported increased disclosure efficacy and decreased disclosure anxiety and worry. Qualitative themes for disclosure issues included distress in social network, concern for others, and institutional support. Implications for theory and research, use and tailoring of the intervention, and decreasing health disparities are discussed.

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African Americans face health disparities in the United States, more so than other racial and ethnic groups (Jackson et al., 1996; Mead et al., 2008). This disparity stems, in part, from racism, discrimination, and higher stress than other racial and ethnic groups (Jackson et al., 1996). Despite some potential protective factors such as strong social ties and self-motivation, African Americans especially are subject to disparities from multiple sources, including in access to healthcare. This article focuses on one example of convergence of disparities, those affecting urban African Americans living with human immunodeficiency virus infection/acquired immunodeficiency syndrome (HIV/AIDS), a medically underserved group that is stigmatized. When African Americans are also HIV+, they potentially experience a double burden when the disease is coupled with difficulties receiving equitable services and treatment. To explore how disparities affect this group, we developed and piloted a brief disclosure intervention to increase patient empowerment around

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HIV disclosure and facilitate assessment of the risks and benefits of HIV disclosure decisions to maximize disclosure outcomes in social networks. The literature review addresses African American HIV health disparities, locates disclosure as a key factor in addressing disparities, and introduces the Brief Disclosure Intervention to begin to address disparities in this context.

African Americans and HIV/AIDS

The HIV epidemic enters its fourth decade with over 1 million people in the United States alone living with the disease (CDC, 2011b). The group most affected by the HIV/AIDS epidemic in the United States is African Americans (CDC, 2011a). U.S. African Americans accounted for 44% of new HIV infections in 2009, yet they represented only 14% of the U.S. population. In comparison, Latinos accounted for the second highest number of new HIV infections at 20% and represented approximately 16% of the population.

Many social problems contribute to and complicate HIV/AIDS for African Americans, including stigmatization, racism, incarceration, and homophobia (CDC, 2011b). The risk for HIV/AIDS increases with the proportion of people living in poverty. A quarter of African American families live in poverty with more than one in five African Americans uninsured; in contrast, one in eight Whites are uninsured (Mead *et al.*, 2008). African Americans are more likely to delay getting tested for HIV/AIDS and, when diagnosed, either do not access care in a timely manner or intermittently participate in treatment (CDC, 2011a). For African Americans, mortality-related productivity losses are 16% higher than for Whites, and direct medical costs are 13% lower. These results are attributable to later stage diagnosis, delays between diagnosis and treatment, and less access to antiretrovirals for African Americans (Hutchinson *et al.*, 2006).

HIV+ African Americans in New Jersey

National trends are consistent with New Jersey HIV/AIDS cases. One in 62 African Americans in New Jersey is living with HIV/AIDS compared to 1 in 701 among Non-Hispanic Whites. This study was conducted in two of the top 10 NJ cities for HIV+ African Americans; in addition, these two cities are in the top 10 for highest percentage of the population below poverty level. In combination, African Americans comprise over 25% of the population below poverty level in both cities. Although there is significant HIV/AIDS burden for African Americans in the United States generally and more specifically in New Jersey, one specific feature that can affect how African Americans manage their HIV infection is disclosure, or how they share information about their infection and disease. HIV disclosure has the potential to increase social support and access to resources that can decrease disparities (and new HIV cases).

Disclosure as a Key Issue for HIV/AIDS

When people are diagnosed with HIV, one of their most troubling decisions is with whom to share the diagnosis, a phenomenon labeled “disclosure.” Nondisclosure

results in a level of social isolation that can impede access to support from social network members and, consequently, can exacerbate health disparities. For example, without disclosure, people living with HIV/AIDS (PLWHAs) may be unable to access assistance from their networks for transportation to appointments, reminders to take medication, and emotional support. Alternatively, HIV disclosure is a predictor of many quality-of-life outcomes such as partner support (e.g., Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004), lower levels of depression (e.g., Petrak, Doyle, Smith, & Skinner, 2001), and retention in HIV care (e.g., Stirratt *et al.*, 2006; Wohl *et al.*, 2011). With the barrage of psychosocial issues confronting them, PLWHAs could benefit from disclosing their diagnosis in order to (a) gain access to social support (e.g., Kalichman *et al.*, 2003), (b) facilitate adherence to complex medication regimens (e.g., Stirratt *et al.*, 2006), (c) reduce psychological distress (e.g., Kalichman *et al.*, 2003), and (d) decrease further transmission of HIV (e.g., to sexual partners). Disclosure has the potential to facilitate each one of these benefits that can, in turn, reduce disparities.

Building on the broader literature on disclosure and privacy, research specifically explores disclosing HIV status (e.g., Greene, Derlega, Yep, & Petronio, 2003; Maiorana *et al.*, 2012). Some of this research points to the role of social networks in HIV disclosure decisions. For example, Rice, Comulada, Green, Arnold, and Rotheram-Borus (2009) found that PLWHAs were more than two times as likely to disclose to a member of their social network if the social network member provided social support and ten times more likely to disclose to a member who they believed was HIV+. Research also explores reasons for and against HIV disclosure (e.g., Black & Miles, 2002; Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Gaskins *et al.*, 2011), the anticipated and actual reactions to HIV disclosure (e.g., Greene & Faulkner, 2002), and targets for HIV disclosure (e.g., Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Petrak *et al.*, 2001; Rice *et al.*, 2009). Miller and Rubin (2007) identified several strategies used to accomplish HIV disclosure, including using a third party to disclose, indirectly revealing positive status (hinting and gradual disclosure), and disclosing to church pastors.

One approach to clarify the HIV disclosure decision-making process is to examine risks and benefits of disclosure. Some *benefits* of HIV disclosure include closer relationships (e.g., Derlega *et al.*, 2004; Greene *et al.*, 2003), social support (e.g., Parsons *et al.*, 2004), safer sex practices (e.g., Parsons *et al.*, 2004; Smith, Rossetto, & Peterson, 2008), and decreased perceived stigmatization (e.g., Lung *et al.*, 2012; Maiorana *et al.*, 2012). Some *risks* include negative emotional responses (e.g., Greene & Faulkner, 2002), inability to control information (e.g., Gaskins *et al.*, 2011; Greene *et al.*, 2003), increased stigma (e.g., Black & Miles, 2002; Gaskins *et al.*, 2011), and isolation (e.g., Catz, Gore-Felton, & McClure, 2002). Balancing these risks and benefits are central to how PLWHAs can use disclosure to increase social support.

One feature absent from the expanding HIV disclosure literature is a specific intervention or guidance for PLWHAs that exclusively focuses on how to productively navigate these disclosure decisions. Researchers have developed programs to help PLWHAs manage psychosocial, social, and health aspects of their condition such as

PwP programs (Prevention with Positives; see Maiorana *et al.*, 2012). Many of these programs are group oriented (limited tailoring), and all require multiple sessions. Some of these programs address disclosure as one component, but it is not the main focus. Thus, a gap in these programs is a need for individually tailored brief interventions that can be adapted for people facing significant health disparities. To address this gap, we developed an intervention for HIV+ African Americans to help them consider to whom they might disclose; we called our intervention the Brief Disclosure Intervention (BDI).

Brief Disclosure Intervention (BDI)

The Brief Disclosure Intervention (BDI) is guided by a theoretical framework, the disclosure decision-making model (DD-MM; Greene, 2009; see Checton & Greene, 2012; Greene *et al.*, 2012). The DD-MM proposes predictors of whether a person will disclose a health issue such as HIV/AIDS. These predictors include assessment of information (stigma, prognosis, symptoms, preparation, and relevance to others), assessment of the receiver (relational quality and anticipated response), and disclosure efficacy. Disclosure efficacy is the discloser's belief that he/she is able to share information that will result in a desired outcome. If information assessment and receiver assessment are positive and efficacy is high, then disclosers may explore specific strategies to share the diagnosis. Although each of the variables in the DD-MM has separately been the focus of privacy research, they have not previously been operationalized and combined into a health decision-making model (see Greene (2009) and Greene *et al.* (2012) for representative research on these variables). The DD-MM adds to the privacy literature by identifying how people balance these factors in decisions to share, extending the dimensions of information beyond valence, and applying the model to health contexts. The BDI applies the DD-MM by focusing on evaluating resources or options for disclosing to increase individuals' beliefs (efficacy) in their ability to successfully share (or conceal) a difficult piece of information, the HIV diagnosis.

The BDI format and tailoring is founded on brief motivational interviews (BMIs). The BMI tradition consists of a brief intervention with a single or multiple sessions of engaging motivational discussion, each lasting from a few minutes to 1 hour, through which participants are made aware of current behaviors. The goals of motivational interviewing are to establish rapport, elicit change talk from the interviewee, and establish commitment language from the interviewee (Miller & Rollnick, 1991). BMI provides health care practitioners with a shortened version of an intervention to use with limited time (Miller & Rollnick, 1991). The BDI uses a risk/benefit assessment approach and incorporates the three main DD-MM assessments of information, receiver, and efficacy. The BDI is designed to facilitate patients' analysis of a series of potential risk decisions, in this case disclosure. The focus is on analyses of options and techniques for sharing, as well as identifying potential reactions from the recipient and maximizing positive reactions. The practice with specific network members targets disclosure efficacy.

A trained facilitator delivers the intervention to individual HIV+ participants in three phases; the phases are progressive and build on each other. In *Phase 1*, participants reflect on advice to give other HIV+ individuals if/when sharing diagnoses. This initial phase frames disclosure issues in a general way, guiding participants in a less threatening manner to consider “disclosure advice” to others. The stem question asks, “If you were telling someone else about how to share their HIV status, what would you recommend? What would you say works well?” and follows by asking about six disclosure strategies identified in prior literature (e.g., Greene *et al.*, 2003; Miller & Rubin, 2007): planning, location, non-face-to-face, practice, gradual disclosure, and hinting. If participants are unfamiliar with a strategy (e.g., do not know what it is, such as non-face-to-face disclosure), then the facilitator describes it and encourages analysis and participation.

After these concepts are introduced generally, *Phase 2* asks participants to describe particular strategies that they would use to disclose their own HIV status in the future. Phase 2 includes additional strategies beyond the six raised in Phase 1: third party (asking another to disclose), taking another (third) person along when disclosing, and testing reactions. With each strategy raised in Phase 2, facilitators ask participants to think about the pros and cons of using the strategy to reinforce the risk/benefit assessment. Facilitators use follow-up and probing questions to encourage elaboration and in-depth processing. This dialectical portion is crucial because it focuses participants on balancing rewards and costs and also prepares them to think about other difficult disclosure decisions. Finally, in *Phase 3*, participants are asked to think about two or three people to whom they have not yet disclosed but might in the next 6 months and how they might share the diagnosis. In this phase, the participants are led through analysis of the disclosure strategies for two people that they have not yet told; this is the most tailored feature of the intervention, focusing on risks/benefits of sharing the diagnosis with these specific people and applying the potential strategies reviewed.

Research Questions

On the basis of the preceding review, this project developed the BDI, explored preliminary effectiveness, and gathered data to inform subsequent adaptation for African Americans with HIV. The project combines qualitative and quantitative data to initially test a disclosure intervention and propose refinements for optimal tailoring for a distressed group. We also established our ability to recruit and deliver the developed intervention. We proposed two research questions. RQ1: Is there evidence for preliminary effectiveness of the BDI on efficacy measures? Beyond intervention effectiveness, we wanted to examine how to refine the BDI to optimize its use for this population. To do this, we explored African American PLWHAs' reports of disclosure and nondisclosure to specific members of their social networks. RQ2: What issues did African American PLWHAs identify that either facilitated or inhibited HIV disclosure?

Methods

Participants

Participants ($N = 43$)¹ were HIV+ African Americans living in urban and suburban New Jersey. The sample included 18 males and 25 females ranging in age from 20 to 64 ($M = 47.31$, $SD = 10.12$). Individuals identified as heterosexual ($n = 32$) and homosexual ($n = 10$; 1 not reported). Level of education was distributed across three groupings: not completed high school ($n = 15$), diploma or GED ($n = 15$), and completed more than high school (e.g., “some college” or associate’s degree, $n = 13$).

All participants were clients of a large AIDS Service Organization (ASO) in New Jersey, a state with more than 75,000 people living with HIV (5th highest in the United States). Most individuals had been diagnosed with HIV in the last 10–12 years ($n = 23$, 54%), with a range of 2–29 years since diagnosis ($M = 11.88$ years, $SD = 7.79$).² Individuals had been clients of the ASO for an average of 3.65 years ($SD = 4.48$), ranging from 10 months to 24 years (at Time 1). Individuals reported contracting HIV through sexual contact ($n = 35$), IV drug use ($n = 4$), prenatally ($n = 1$), or were “unsure” ($n = 3$).

Procedure

We developed the intervention and interview schedule, working with ASO staff to refine the intervention and interview questions. The intervention was individually delivered within a structured interview. We pretested the interview schedule (including the intervention) with 10 PLWHAs and ASO staff. We provided the ASO with a list of study inclusion criteria (HIV+, disclosed to some but not all social network, having disclosure concerns, and not being AIDS advocates such as AIDS speakers or working for the ASO).³ The ASO staff recruited participants meeting these criteria. We developed a social network map (i.e., listing members of family, close friends, coworkers, etc.) and then asked if each specific person knew the participants’ HIV status; finally, we asked why PLWHAs disclosed (or not) to each person. What resulted from the recruitment strategy were stories about disclosure that evidenced variability in individuals’ degree of comfort with disclosure in their social networks.

We conducted all interviews in private rooms at one of two ASO locations. Interviews were conducted by four trained graduate students.⁴ After obtaining consent, the interviewer asked for permission to audio record the interview. Interviews ranged from 20 to 72 minutes ($M = 42$, $SD = 15.52$), generating 11–36 pages of transcribed text ($M = 22$, $SD = 6.44$). Undergraduate students transcribed interviews, with transcripts verified by a second student.

This project included a baseline structured interview with 6-month follow-up. Both Time 1 and Time 2 surveys were 30–45 minutes long, with the experimental group additionally receiving the 15–20 minute intervention. Participants were assigned either to the BDI condition ($n = 17$) or to the control group ($n = 18$; delayed intervention).⁵ Of the 35 individuals who participated at Time 1, 27 returned at Time 2 (77%; 13 from the BDI condition and 14 from the control group). Because we established initial positive evidence of BDI effects at Time 1 (pretest-immediate

posttest), we recruited eight additional participants at Time 2 to receive the BDI, along with completing pretest and immediate posttest measures.⁶ Participants who completed the Time 1 interview received a \$25 VISA card and an additional \$35 card for completing the 6-month follow-up.

Measures

To establish initial effects of the BDI and opportunities for tailoring for this population, we employed both quantitative and qualitative measures. The interview was generally open-ended, with several closed-ended items (the quantitative measures).

Quantitative measures. Several quantitative indicators estimated BDI effects, and these measures were used at Time 1 at the beginning (pretest) and end of the interview (immediate posttest) and at Time 2 (delayed posttest) at the beginning of interview. Measures included two scaled items and one coded item. We relied on single-item measures because of the format and repetition; the items were modified from prior research (e.g., Checton & Greene, 2012; Greene et al., 2012). Pilot testing led us to modify the prior 5-point format to a 0–10 scale for ease of use with the population and oral administration.

Disclosure efficacy. Disclosure efficacy was measured by a single item asking, “If you were to put a number between 0 and 10 on how confident you are about telling someone you are HIV+ . . . how confident are you about telling someone you are HIV+ ?” The sample reported disclosure efficacy from 0 to 10 ($M = 6.69$, $SD = 3.80$) with a higher score indicating increased efficacy. Analysis of this item involved pretest and delayed posttest measurement points.

Disclosure anxiety. Disclosure anxiety was measured by a single item stating, “If you were to put a number between 0 and 10 on how anxious you are before telling someone you are HIV+ . . . how anxious are you before telling someone you are HIV+ ?” The sample reported disclosure anxiety from 0 to 10 ($M = 6.58$, $SD = 3.58$), with a higher score indicating greater anxiety. Analysis of this item involved pretest and delayed posttest measurement points.

Worry about disclosure. Two graduate student coders rated textual responses from transcripts describing worry about disclosure. Coders read participant descriptions and elaborations for the item, “How much do you worry about telling people your HIV status?” One student coded transcripts, with a second coding 20% ($r = .94$). The sample described worry about disclosure from 0 to 5 ($M = 3.06$, $SD = 1.66$), with a higher score indicating increased worry about disclosure. Analysis of this item involved pretest and immediate posttest measurement points.

Qualitative measures. Qualitative measures included open-ended questions asking participants to describe stress in regard to disclosing their HIV status (e.g., “How anxious are you about people finding out that you are HIV+?”). All participants answered questions about their social networks (e.g., family, close friends, neighbors, and religious groups), to whom they had disclosed their HIV+ status (if yes, how

did the person respond?), and the reasons they had and had not disclosed. Questions specific to the intervention group asked them to explain why or why not they would use the different disclosure strategies (e.g., third-party disclosure, non-face-to-face, testing reaction) and the risks and benefits of implementing each strategy.

The qualitative data were analyzed by thematic analyses with the goal to identify what features of disclosure were salient in PLWHAs' reasons for sharing/not sharing in their social networks. Open coding began with a line by line reading of each transcript, identifying units of data, and assigning each unit a conceptual code (Strauss & Corbin, 2008). After each data unit was assigned a code, it was compared to previous data units to determine if it represented the same or different meaning using the constant comparison method (Strauss & Corbin, 2008). Similar codes were clustered into larger categories that were informed by the DD-MM (Greene, 2009). The coders agreed that three broad categories represented the data (distress in social network, concern for others, and institutional support), with subcategories. Data exceeded saturation; the results present representative examples.

Results

To explore the effectiveness of the BDI (RQ1) and how to refine it for this distressed population (RQ2), we present two sets of results. We begin with results for BDI effectiveness.

Quantitative Results

The quantitative data were analyzed by a series of analysis of covariance (ANCOVAs); level of significance set at $p \leq .05$. We examined time diagnosed, t-cell count, and viral load as potential covariates. T-cell count and viral load were not significant; after adjustment for length of time diagnosed HIV+ there were significant differences between the control and intervention groups in outcome variables.

A repeated-measure ANCOVA showed an increase in intervention group disclosure efficacy when comparing pretest and delayed posttest scores for the 27 participants who completed both Times 1 and 2. There was a significant effect for length of time diagnosed, $F(1, 25) = 14.24, p < .001, \text{partial } \eta^2 = .36$. Controlling for length diagnosed, there was the expected condition by time interaction $F(1, 25) = 3.45, p < .05, \text{partial } \eta^2 = .12$ with an increase in disclosure efficacy in the intervention group from Time 1 pretest to delayed posttest (pretest $M = 2.36, SD = 1.46$; delayed posttest $M = 3.25, SD = 1.54$).

A repeated-measure ANCOVA indicated a decrease in intervention group disclosure anxiety when comparing pretest and delayed posttest scores for the 27 participants who completed both Times 1 and 2. There was an effect for length of time diagnosed HIV+, $F(1, 21) = 7.12, p < .05, \text{partial } \eta^2 = .25$. Controlling for length diagnosed, there was the expected condition by time interaction $F(1, 21) = 20.54, p < .001, \text{partial } \eta^2 = .49$ with a decrease in disclosure anxiety in the intervention

group from Time 1 pretest to delayed posttest (pretest $M = 4.41$, $SD = .89$; delayed posttest $M = 3.76$, $SD = 1.22$).

A repeated-measure ANCOVA indicated a decrease in intervention group worry about disclosure when comparing pretest and immediate posttest scores for all participants who completed the first portion of the study ($N = 43$). There was an effect for length of time diagnosed HIV+, $F(1, 40) = 8.04$, $p < .05$, partial $\eta^2 = .17$. Controlling for length diagnosed, there was the expected condition by time interaction $F(1, 40) = 3.70$, $p < .05$, partial $\eta^2 = .08$ with a decrease in worry in the intervention group from pretest to immediate posttest (pretest $M = 3.68$, $SD = 1.49$; immediate posttest $M = 2.80$, $SD = 1.22$).

Qualitative Results

RQ2 examined how to adapt the BDI for challenges of this distressed group by focusing on issues that facilitate and inhibit HIV disclosure in social networks. Recurrent themes were distress in social network, concern for others, and institutional support. We describe findings, followed by recommendations for tailoring; parenthetical numbers refer to participant ID.

Distress in social network. Participants (and social networks) experienced many health, familial, and financial difficulties that affected disclosure decision-making. These challenges were HIV prevalence in the social network, varied family structure, economic distress, and substance use. This distress in social networks functioned to both hinder and facilitate disclosure.

Presence of HIV in the social network. There was high prevalence of HIV/AIDS in participants' social networks. Of the 43 participants, 15 mentioned at least one person had died from AIDS in their family or close network. An additional 22 participants knew at least one person with HIV/AIDS.

Presence of HIV in network as positive. Some participants shared their HIV status because the disclosure recipient was also HIV+ or the recipient knew someone else with HIV/AIDS (see Derlega *et al.*, 2002, 2004; Rice *et al.*, 2009). For example, one participant explained that she disclosed to her friend because: "Her dad passed from HIV and she took care of him . . . So she might understand it a little better" (02). One participant described an improved relationship with her stepmother: "It drew us closer as well because my stepsister died from the virus . . . I told them and actually she [Stepmom] gave me more information than anybody" (14). Thus, prior behavior (e.g., having taken care of someone with AIDS, having provided specific support for PLWHAs) is viewed as indicating a likely positive response to current HIV disclosure and being likely to serve as a resource.

Social networks with HIV+ members and members who knew people with HIV provided "safe" opportunities for HIV/AIDS disclosure. This availability of similar others sets the context for the disclosure event. One participant summed up the benefit of disclosing to a similar other as, "They [are] like me, we are the same . . . I can communicate with people who have the virus better than I can communicate

with someone that doesn't" (06). For some participants, HIV presence encouraged disclosure and provided additional access to social support.

Presence of HIV in network as negative. Observations of negative treatment of PLWHAs consistently inhibited disclosure (see Gaskins *et al.*, 2011). Some participants witnessed PLWHAs being treated as if they had a contagious condition (see Leary & Schreindorfer, 1998), and this inhibited disclosure. One participant reported, "I had had uncles who had had the virus and I kept seeing how people were treating them . . . My uncle had gotten this girl pregnant and nobody wanted to touch the baby . . . and I said, 'No, we'll wait [to tell others in the family]'" (19). Participants stated repeatedly that they would not share with someone if they thought the person would stigmatize them, echoing components of the DD-MM (anticipated response and information).

Beyond stigma, the abundance of HIV-related deaths in participants' social networks often reduced the size of those networks dramatically. One participant described the destruction of her peer network: "There was a crowd I'd been hangin' with, and then four people in that crowd had just been like BOOM, BOOM, BOOM, and died like that . . . they had died of AIDS . . . Now out of that big crowd only two of us left" (17). For this participant and others, significant portions of their social network are dead, dramatically reducing available social support. Another participant described how the disease has devastated his network: "I've watched many, many friends die from the virus" (33). For some participants, the extreme loss reduced disclosure opportunity and caused them to withdraw and not share.

Varied family structure. Some participants described family structures that affected the size of their available social network and relationship quality with network members, both facilitating and at times hindering disclosure. Some participants were not in contact with their parents (or children). For some participants, extended family/kin structures provided good disclosure targets: "My Aunt X . . . she is more of a mother than my mother. I would go, well, she was very supportive" (32). For others, varied family structure was a negative experience that decreased potential support: "Cause me and her [Aunt] didn't used to get along . . . she had called the doctors [state] on me and took my kids, three of them" (44). Thus, PLWHAs reported these influential family structure experiences affected disclosure and available potential social support. Participants' perceptions of family history were crucial in some disclosure decisions. One participant described being raised by grandparents: "My mother didn't raise me . . . I'm not comfortable telling her a lot of things what's going on as far as my health or anything in my life" (32). This participant's family past hindered his ability to share with his mother and potentially receive her support.

Economic stressors. Housing, finances, and unemployment were raised as concerns for 14 of 43 participants, and these economic stressors influenced disclosure decisions, both positively and negatively. In some cases, economic distress facilitated disclosure to meet a need for some form of assistance (Derlega *et al.*, 2004; Greene *et al.*, 2003). Instrumental support was often provided in the form of housing and monetary

loans until participants were “back on their feet.” One participant discussed why she shared: “I don’t work right now . . . so I lost my apartment because I had no money and she [friend] let me come stay with her” (08). Another participant also described sharing for instrumental support: “He [friend] looks out for me. I am not working right now, so he helps me out with a few dollars . . . Whenever I need a ride, he is right there” (41). Some participants chose to access support only within the family, and this may be sufficient in highly supportive families, but others felt the need to supplement their networks.

Participants also mentioned economic distress regarding unstable housing that affected disclosure. One participant, frustrated waiting in transitional housing, described emotional support provided after disclosure as, “[He helps me with] motivation. When I feel defeated a lot, because of where I live at, I’ve talked to him a lot about that, so they say, ‘It’s not going to last long, just get through it, you are there to get the housing, so get the housing and leave’” (05). Participants reported spending a great deal of energy worrying about housing: “Health wise I think I’m doing kinda good, but I’m afraid it’s going to get bad because of a housing situation. I’m afraid I’m going to be homeless” (17). For these participants, stability of housing was a significant stressor, one that at times put them in positions where they felt “pressured” to disclose their HIV status. Thus, economic stressors sometimes but not always motivated participants to share to obtain social support (often instrumental).

Substance use. Participants referred to the effects of their own and social network members’ past and present substance use on HIV disclosure. Of the 43 participants, 13 referred to personal substance use (and others’ use), and an additional three referenced network members’ drug use.

Participant substance use. Participant substance use emerged primarily as inhibiting disclosure. If participants decided to share HIV status, they were often asked, “How did you get it?” One lesbian participant who contracted HIV through drug use described, “They were like confused, they said ‘Well, how’d you get it?’ . . . I think the only one that really knew was maybe my sister . . . And a couple of family members that are in the drug world . . . they knew where I got it, from shooting dope . . . (The others) wanted to ask me, ‘How the hell did you get it?’” (17). For this woman, questions arose about contracting HIV and this decreased her willingness to share because she did not want to address her prior drug use.

Some participants alienated family members due to their own drug use, increasing their social strain and decreasing access to potential support resources. One participant shared that he did not tell his family because he was secretive about the drug-using part of his life: “At the time I didn’t tell them [family]. I was doing drugs, abusing drugs at that time” (38). For some participants, they did not want to share diagnoses until the relationships were repaired or they had proven their sobriety. One participant wanted to share with her son, “When he comes home, he is going to see that I changed . . . You know, I hurt a lot of my family, but I am alright today” (06).

Social network member substance use. Others' substance use emerged as a potential facilitator and inhibitor of disclosure. Some current or past drug using network members were described as more understanding and less intimidating as disclosure targets. One participant explained how her sister was an ideal recipient: "She would know . . . We talk about a lot of things, 'cause we have similar ways, like when I was out there getting high, when I was jail wise . . . We had similar things, but she just wasn't in and out [of jail] like I was" (23). Different from this similarity that may increase disclosure, participants who were trying to remain "clean" reported avoiding current substance users and not disclosing. Participants reported an additional concern that current users (or former users who might relapse) might not respect confidentiality if "high." Another participant compared the reactions of siblings and identified the main difference in willingness to share: "Me and my brother had issues with drugs. And I think that is one of the reasons why we are a lot closer, because we can identify on that level of being former addicts . . . My sisters, they've never drank or did drugs. So they don't really understand a lot of things when it comes to addiction" (32). Thus, participant substance use generally inhibited disclosure but others' use both facilitated and inhibited sharing.

Concern for others. Concern for others consistently hindered disclosure (Derlega *et al.*, 2002; Gaskins *et al.*, 2011; Greene *et al.*, 2003). A number of participants' social network members recently lost a relative, experienced poor health, and/or were incarcerated. Disclosure decisions to these people were framed as "too much" for the other to handle (see Derlega *et al.*, 2002). One participant described not disclosing to his cousin: "He just lost his brother of the virus, and I don't want to tell him that I have it and it might just take a toll on him . . . I'm not ready to put the family through that" (21). Another participant described not sharing because her daughter-in-law was in poor health and had recent deaths in her family: "[I would not tell her because] last year she lost both her mom and her dad. All these people got dead people" (02). For these participants, not only did they have their own stress and disparities to manage but also their social networks were distressed, limiting potential support.

Others' incarceration also emerged as inhibiting disclosure. Of the 43 participants, 19 had at least one person who was incarcerated in their social network. One participant described why he had not shared with his nephew: "Well, he is actually in prison. And I feel like he's got a lot to deal with just to get through a day, so he don't need to [know my HIV status]" (35). Another mother described a similar response: "[I haven't told my son] because he has been incarcerated for most of his life . . . We are getting to know one another again . . . It's not really important for me to tell him right away" (05). Thus, concern for others in this group served to inhibit disclosure.

Institutional support. Neighborhood institutions provide access to resources such as instrumental, informational, and emotional support. Churches, ASOs, and substance abuse programs are relevant institutions related to distress and disclosure that emerged in this study.

Church. Religious institutions (churches in this sample) emerged as both positive and negative influences on disclosure decisions and social support.

Positive disclosure at church. Eight of the 11 participants who regularly attended church mentioned the benefits of disclosing at church, including acceptance, feeling part of a community, and access to social support. One participant described, “Deacon X and his wife were the first people outside of God that knew . . . Deacon X and his wife kind of accepted me and helped me out” (41). Participants often identified churches as providing instrumental and emotional resources. One participant reported emotional support: “Pastor Y knows as well. I told him when I joined the church . . . And we sat down and we talked, and I confided in him . . . You could tell him you were dying of leprosy and he would still hold your hand” (41). Other participants described the disclosure decision-making process before sharing. One participant provided her reason for intentional health disclosure: “Because we [pastor’s daughter and me] were having a conversation and we were talking about somebody and she had mentioned somebody [HIV+], and it wasn’t a bad way . . . I’m definitely going [to tell] my church” (17). For this person, HIV disclosure was linked to the accepting responses of a church member. Participants with positive experiences were much more likely to be willing to disclose their HIV status to other church members and saw church as decreasing stress and sometimes also providing food, clothing, and temporary housing.

Negative disclosure at church. Other participants reported negative church experiences that hindered disclosure and social support. Three of the 11 participants who regularly attended church mentioned disadvantages of disclosing at church or to specific church members. One participant summed up her view as, “I tried that church thing, and it was a total disaster” (01). Some participants identified negative anticipated outcomes (e.g., passing judgment and making attributions) as inhibiting disclosure to church members. Concerns specifically mentioned related to homophobia, drug use, and promiscuity. One participant described church congregations: “Personally, I wouldn’t tell because churches are notorious for not being very supportive of HIV . . . They also tend to pass judgment on your life style” (38). The association with stigma is clear where participants reported negative church disclosure experiences. Participants believed some parishioners viewed HIV/AIDS as a contagious condition (see Leary & Schreindorfer, 1998). One participant shared, “There were these two ladies [at church] . . . I had all intentions of telling them my status . . . So they were talking, and they said . . . ‘You know [name] was by here and she’s drinking out of our cups and sitting on our toilet and we know she got AIDS.’ And I said, ‘I can’t tell them, ‘cause they’re not ready’” (01). Participants also acknowledged that churches were large and diverse groups, and this made it more difficult to control information such as telling one person and not others in the church (see gossip, Greene *et al.*, 2003; Venetis *et al.*, 2012).

Other neighborhood institutions. Participants mentioned other institutions in relation to facilitating disclosure. ASOs and substance abuse programs (e.g., Narcotics

Anonymous or Alcoholics Anonymous) provided access to similar others and offered safe spaces to “open up.”

Institution-based support groups were seen as substitutes for or supplements to small and/or strained social networks. One participant described his social situation as, “I don’t make that many friends . . . Mostly would be at the groups that I go to. They all HIV+, so they all know” (12). Other participants identified various types of social support provided by these neighborhood institutions. One participant described the support provided by an ASO: “People from the [acronym] program . . . They test you and help you with the results if it is positive . . . They help you deal with things and, you know, they look out for you” (41).

Other participants who are recovering substance users expressed the importance of recovery programs in their disclosure and social support. These programs were described as helping participants stay focused, make positive decisions, and “fight temptation.” One participant shared, “And then I’m tackling the substance abuse, you know, so I have to go to groups and stuff . . . I’m trying to stay focused, but on a lot of days it is really hard” (36). Participants valued the anonymity of these groups and saw recovery as a key issue in their disclosure decisions.

BDI Tailoring

Results suggest how the BDI can be tailored for urban HIV+ African Americans to better assess distress, concern for others, and institutional support. To begin, there was a great deal of distress in these social networks, so we plan to adjust the BDI to focus more on how distress affects access to support. First, because HIV-related and other deaths decreased the size of participants’ social networks, we can encourage participants to consider ways to supplement their networks, such as joining support groups. We also can recommend sharing their diagnosis with a fellow PLWHA or a person who cared for PLWHAs; this may maximize positive anticipated responses and increase beneficial outcomes. Second, family structure often inhibited disclosure. Participants not in contact with family members generally reported increased stress and decreased social network availability. We will include specific items in the social network measures about households where participants grew up and current/past contact with family members to help participants more thoroughly assess the extent of their social network. Third, housing and income were key features in economic stress. In some cases, this stress facilitated disclosure to gain instrumental support, but more often the stress inhibited disclosure if the person felt too vulnerable. Participants felt especially vulnerable if they disclosed to meet a tangible need and family or friends denied the request (e.g., to move in, care for children, loan money). BDI tailoring will include asking specifically about housing and economic stability to better help participants assess the benefits and risks of disclosing their diagnosis when doing so to obtain tangible support. Finally, although substance use could be a foundation for similarity and encourage disclosure in some cases, it also could invite judgmental reactions that would decrease disclosure and increase stress. BDI tailoring will help participants to consider the impact of substance use on disclosure decisions.

The second BDI tailoring feature regards how concern for others consistently inhibited participant HIV disclosure. These social networks had significant member loss (i.e., death), poor health, and incarceration, factors that led participants to assess these specific members as “unavailable” for social support and already “managing too much.” This is another example of how this sample faces decreased access to resources, a circumstance that can contribute to health disparities. The BDI captured this phenomenon well, yet we still underestimated the levels of loss and distress experienced in these networks. We will tailor the BDI to encourage participants to carefully assess the risks and benefits of disclosing to social network members who themselves are facing significant stressors.

The third BDI tailoring feature is institutional support. Some churches and members provided tremendous resources for PLWHAs, yet some members were viewed as displaying negative moral judgments about HIV. Thus, churches can be both productive sources of coping and sources of intolerance that may magnify disparities. For participants who belong to religious groups, we will include these groups in the BDI risk/benefit assessment (i.e., as a disclosure target). For all participants, we will ask how similar others in support groups can be sources of support to encourage utilization of these positively viewed resources.

Discussion

This study explored a disclosure intervention designed to support PLWHAs and, by extension, to increase social support that can potentially reduce health disparities for HIV+ African Americans. The intervention was designed to increase patients’ sense of empowerment and awareness of options regarding sharing HIV diagnoses, along with increasing skills for assessing potential responses to HIV disclosure. These skills and empowerment (efficacy) are key conduits to obtaining social support.

This article provides initial evidence for effects of the BDI, including increased disclosure efficacy and decreased disclosure anxiety and worry (RQ1). The primary advantage of the personally delivered BDI is the ability to tailor it to the patient’s social network, thus motivating more careful processing of the feedback and more productive self-evaluation. This tailoring is expected to motivate the individual to engage in a meaningful risk/benefit assessment for each disclosure decision and increase awareness of alternative strategies for disclosing. In addition, the format of the feedback allows the participant to interact with the intervention facilitator individually (e.g., ability to ask questions and receive answers). The main disadvantage is the relatively high cost of delivering the intervention (including training and labor), although this cost estimate is reduced because of the intervention brevity and the current ASO expectation of one-on-one delivery of HIV services through case workers or social workers. Thus, after a larger efficacy trial, the BDI has strong potential for translation and dissemination.

After establishing the initial BDI effects, we next asked what issues facilitate and inhibit disclosure by HIV+ African Americans. This information would give us

guidance on tailoring the BDI for this distressed population (RQ2). First, participants reported a wide range of distress including HIV/AIDS in their social network, varied family structure, economic instability, and substance use. Next, participants described how concern for others inhibited disclosure to specific network members. Finally, participants described how institutions influenced disclosure patterns. The BDI intervention can be tailored to assess all these concerns, which will provide participants with increased awareness of options to disclose to increase social support.

Implications

There are at least four groups that could be positively affected by the proposed intervention. First, by evaluating risks and benefits of specific disclosure strategies and analyzing specific potential disclosure decisions, PLWHAs themselves would have greater resources to cope with difficult disclosure decisions; long-term, these skills should increase available social support, positive disclosure outcomes, and access to related health benefits. Second, some people who may be at risk for HIV infection (e.g., sexual partners) could be encouraged to reduce potential risk if they were recipients of HIV disclosure. Third, families and support systems of those with HIV may be better able to provide effective social support and decrease stress for PLWHAs if decisions about who knows (and should know) the PLWHA's HIV status are clarified (including information boundaries or who can be told, see Venetis *et al.*, 2012). Finally, the intervention would be a valuable tool for health professionals to help patients manage stress and anxiety surrounding disclosure decisions. Thus, the proposed intervention has potential for significant impact, and its brevity makes it more likely to be implemented than current longer multisession interventions.

The work presented here has several practical implications related to health disparities. In these data, it was clear that many participants' social networks were devastated by HIV/AIDS, which reduced potential sources of social support. Participants' descriptions of their social networks were riddled with death, incarceration, and in some cases alienation; for others, however, robust extended kin networks were common; still others had created new networks through similar others such as support groups, extended family networks, and/or religious groups. Disclosure interventions designed for use within this community must be tailored specifically to the social network needs of this population and include alternative sources of social support for those with significant member loss.

HIV+ African Americans experience stigma from multiple sources. They suffer not only responsibility attribution where they are seen as at "fault" for their infection (see Leary & Schreindorfer, 1998) but also from the perception of having potential to "infect others." The seemingly insurmountable disparities for this population heighten concern about HIV disclosure and underscore the importance of an intervention such as the BDI tailored to the needs of African American PLWHAs. On the basis of the BDI and stigma findings, the intervention could further explore increasing skills surrounding indirect disclosure strategies such as hinting, testing reactions, and gradual disclosure to maximize protection and risk avoidance.

Our results also have implications for theory, specifically for using the DD-MM (Greene, 2009). Participants referenced each of the three DD-MM components (information, receiver, and efficacy) in discussing disclosure decisions. Information (five subcomponents in the DD-MM) received the least attention in prior research, often reduced to valence, yet our participants demonstrated sophisticated consideration of multiple information components in decisions to share. The overall *stigma* findings are not new: People are unlikely to share if they believe that others will judge them. For *prognosis*, participants stated that they would not share with certain people “until the very end.” This is similar to findings for visibility where participants who were unsure of another’s reaction described waiting until the *symptoms* were visible to share. *Preparation* appeared least in these data, but participants with prior substance use or prior multiple sexual partners described how they—and others in their social network—anticipated the diagnosis, making sharing easier in some cases. Finally, some participants reported strong moral obligations to consider *relevance to others* and would tell any sexual partner. Overall, participants’ assessments of the information were multifaceted and both facilitated and inhibited HIV disclosure. This should be a caution to researchers seeking to use a single information indicator such as valence in health research.

The DD-MM also highlights the role of receiver assessment (relational quality and anticipated response) and efficacy, and these influences were also clear in the data. For relational quality, participants repeatedly mentioned telling people they were close to (and telling them sooner) and not sharing with distant others (both emotional and physical distance were mentioned). Anticipated response was raised in both positive and negative ways, depending on the valence of the expected response (e.g., not wanting to be judged versus knowing the person would “be there”). Participants were able to practice assessing anticipated response in the intervention (Phase 3). On the basis of this practice component and application of skills, many participants mentioned that they will feel more confident and have a broader set of skills when they choose to disclose in the future.

Limitations

The present project has some limitations. We tested our intervention with a sample of African American PLWHAs in one northeastern state, and it is difficult to generalize these results to other groups, other stigmatized health conditions, or health conditions generally. Participants were recruited from a large metropolitan area and a midsized city, and disclosure and disparity patterns may be very different for rural areas or smaller cities. The sampling strategy underrepresented PLWHAs not using ASOs or not “in care,” and these are likely to be some of the participants who are most in need of social support (and this intervention) to decrease disparities. This initial test of the BDI also involved a small sample, used limited quantitative measurement, and only followed participants for 6 months.

There was also a range in our sample for time diagnosed, and the BDI was initially designed to target those newer diagnosed who are struggling with disclosure decisions.

However, even 10–20 years postdiagnosis, PLWHAs report disclosure anxiety and must additionally manage disclosure decisions with new network members such as when dating, in employment, or with new friends. If people have been diagnosed for several years and still have not disclosed to most of their social network, they may have very different disclosure and support needs than someone newly diagnosed.

Future Research

Future research should consider further evaluation of the effects of the BDI using more extensive quantitative measures, broader and larger samples, and extended follow-up periods. We conducted quantitative analyses using length of time diagnosed and health status (t-cell, viral load, BMI) as covariates, but future research could explore the size of social networks and proportion of prior disclosure as covariates. Our data do not address how people “weigh” the various components in a decision to disclose, and this is another important area for future research.

Our work suggests that African American PLWHAs, although resilient, face limited and distressed social networks, rendering them in need of supplemented social support to cope with the disease. Future efforts could identify the most significant social networks for African American PLWHAs, for example extended kin, recovery or PLWHA groups, and religious groups. In some cases, selective disclosure to social networks alone could increase access to needed social support. For these cases, the BDI provides important avenues to identify likely supportive recipients so that people may share earlier in their disease course rather than wait until they are even more severely distressed. In other cases, expanding social networks to include nonjudgmental similar others is an important step.

Other research might examine the intersection of the multiple forms of stigmatization experienced within this population in order to make educated recommendations for social services, as well as to provide grounding for policy recommendations. The intervention presented here provides empowerment, skills, and resources by focusing on evaluating risks and rewards to balance and navigate complex relationships. The intervention provides a foundation for PLWHAs to increase positive responses to their HIV disclosures, bettering their opportunities to increase social support. One way that communication interventions can have an impact on this type of significant health disparity is through empowering interventions such as the BDI that provide skills for the population. In the present case, the intervention has the added benefit of brevity and flexibility to maximize individual tailoring.

Conclusion

This project developed an intervention to assist HIV+ African Americans, patients facing unique stressors. The goal of the BDI was to increase PLWHAs' assessment of HIV disclosure options to improve access to social support. Accessing improved social support, in turn, may help to decrease some health disparities for this population. The findings provide initial evidence for BDI effects, in addition to identifying how

the intervention can be tailored to maximize benefits for this population. This is a crucial area where communication interventions can have a significant impact, one that should receive continued attention.

Notes

- 1 This sample is part of a larger study with $N = 59$ PLWHAs (73% African American, 12% Hispanic, 10% White). This article uses data from the 43 African American participants.
- 2 Participants' BMI ranged from 19.13 to 51.37 ($M = 29.45$, $SD = 7.55$). T-cell counts ranged from undetectable to 1,267 ($M = 561$, $SD = 279$), viral load from undetectable to 9,730 ($M = 555$, $SD = 1,641$), suggesting a reasonably healthy sample with some physically distressed participants.
- 3 We did not recruit people who had not disclosed their HIV+ status to anyone because they may not be prepared for an intervention that explicitly emphasizes weighing the pros and cons of these decisions (which might raise perceptions of risk, an ethical concern).
- 4 Each interviewer completed at least two practice interviews. Three interviewers were White women; one was an African American man. We detected no differences by interviewer and combined data for analysis.
- 5 Conditions were assigned initially by coin flip, with alternating conditions after Day 1 to balance representations of participant gender, length diagnosed, and sexual orientation. Interviewers alternated between conditions.
- 6 For the *intervention* group: Time 1 ($n = 17$) included pretest measures at the outset of the interview schedule, unrelated other questions, the intervention, and immediate posttest items at the end of the interview; Time 2 ($n = 13$) began with delayed posttest items and then followed with unrelated questions. For the *control* group: Time 1 ($n = 18$) included pretest measures at the outset of the interview, unrelated other questions, and immediate posttest items at the end of the interview; Time 2 ($n = 14$) began with delayed posttest items and then followed with the intervention (because Time 1 initial analyses demonstrated positive short-term BDI intervention effects). For the *Time 2 intervention only* condition: Measures included pretest items at the outset of the interview, unrelated other questions, the intervention, and immediate posttest items at the end of the interview. Quantitative analyses for disclosure efficacy and disclosure anxiety involved participants in the intervention group and control group who completed pretest and delayed posttest measures ($N = 27$). Quantitative analysis for worry about disclosure included all intervention and control participants, as well as the eight additional participants recruited at Time 2 ($N = 43$). Qualitative analyses also included all 43 participants. We conducted *t*-tests to assess equivalence between these groups and found fewer significant results than would be expected by chance. For demographics and health indicators, there was only one significant difference between control and intervention groups; for self-reported weight, $t(41) = 2.23$, $p = .03$, control participants ($M = 200.11$, $SD = 47.70$) were heavier than those in the intervention ($M = 171.64$, $SD = 36.16$). Follow-up analyses controlling for weight did not change results presented, and we treated this as a minor difference attributable to Type I error. We also explored potential differences between participants who did and did not return at Time 2, and there were no significant differences related to attrition. Finally, we compared the intervention group at Time 1 ($n = 17$) and the Time 2 intervention only group ($n = 8$) and also found no significant differences. Thus, these data were combined for any analyses when possible (i.e., when no delayed posttest was required).

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