



Published in final edited form as:

AIDS Care. 2014 September ; 26(9): 1194–1200. doi:10.1080/09540121.2014.894608.

If you build it will they come? Addressing social isolation within a technology-based HIV intervention for young black men who have sex with men

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Abstract

The rate of HIV infections among young black men who have sex with men (YBMSM) continues to rise at an alarming pace. YBMSM are particularly vulnerable to social isolation and a lack of social support due to experiences with racism and homophobia, which may have implications for sexual risk behaviors. The purpose of this study was to explore perceptions of social isolation and sense of community among YBMSM, the need for and receptivity to social networking features designed to reduce social isolation and build community within an internet and mobile phone-based primary and secondary HIV prevention intervention for YBMSM and to identify strategies to develop these features. Focus groups were conducted with 22 YBMSM ages 20–30 at three sites in North Carolina. Data from the focus groups were thematically analyzed using NVivo. Feelings of social isolation and lack of a sense of community were strongly endorsed by participants with homophobia, lack of opportunities for social engagement, and a focus on sex rather than friendship in interpersonal relationships with other YBMSM cited as contributing factors. Participants were receptive to a social networking intervention designed to reduce social isolation and build community. Recommendations offered by participants to increase acceptability and usability of such features included: availability of information about healthy relationships, the ability to connect with other YBMSM and health care providers, and ensuring the site had ongoing facilitation by the study team as well as monitoring for inappropriate content. The development of a social networking feature of an HIV prevention intervention may present an opportunity to reduce social isolation, build community and reduce risky sexual behaviors among YBMSM. The findings from this study are being used to inform the development of a social networking feature for an existing internet and mobile phone-based primary and secondary HIV prevention intervention for YBMSM.

Keywords

social isolation; HIV intervention; men who have sex with men; social networking; internet

Introduction

Social isolation, or the involuntary exclusion from geographically and identity-bound communities, can fuel and perpetuate health disparities (Wilkinson & Marmot, 2003). In the United States (Garofalo, Mustanski, Johnson, & Emerson), black men who have sex with men (BMSM), report feeling ostracized from white MSM communities due to their race and from black communities due to their sexual relationships (Crawford, Allison, Zamboni, & Soto, 2002; Raymond & McFarland, 2009; Stokes & Peterson, 1998). The resulting social isolation and lack of social support may contribute to negative psychosocial outcomes including feelings of alienation, negative affect, and low self-mastery and self-esteem (Cohen, 2004). These outcomes, in turn, have been associated with decreased exposure to positive health behavior norms and increased sexual risk behavior (Ayala G, Bingham T, Kim J, Wheeler DP, & GA, 2012; Cohen, 2004; Myers, Javanbakht, Martinez, & Obediah, 2003). The implications of social isolation may be particularly important among young BMSM (YBMSM) for whom the rate of new HIV infections continues to rise at an alarming pace (Millett et al., 2012; Prejean et al., 2011; Su, Beltrami, Zaidi, & Weinstock, 2011).

There are few effective interventions available to meet the HIV prevention needs of YBMSM (Johnson et al., 2009; Maulsby et al., 2013). While there are numerous psychosocial and structural barriers to reaching YBMSM (Raymond & McFarland, 2009), some success has been achieved through peer-based interventions that support HIV risk reduction (Jones et al., 2007; Young et al., 2013). Since computer-based HIV prevention interventions have been shown to be as effective as those delivered in-person (Noar, Black, & Pierce, 2009), and YBMSM indicate receptivity to internet-based prevention interventions (Bolding, Davis, Sherr, Hart, & Elford, 2004; L. Hightow-Weidman et al., 2011; L. B. Hightow-Weidman et al., 2012), peer-supported, internet interventions may be a highly effective HIV prevention strategy for hard-to-reach YBMSM.

In 2012, 67% of US internet users (half of all adults) used social media platforms such as Facebook, MySpace and Twitter (Pew Internet and American Life Project, 2013). Among internet users under age 30, 83% used social networking sites (Pew Internet and American Life Project, 2013). Internet-based health interventions have employed social networking components to improve self-management of chronic illness (Hill & Weinert, 2004; Marziali, 2009; Weinert, Cudney, Comstock, & Bansal, 2011), provide mental health services (Lipman, Kenny, & Marziali, 2011), alleviate loneliness among older adults (Fokkema & Knipscheer, 2007), and address HIV risk behaviors (S. Rhodes et al., 2010; Young, Cumberland, et al., 2013). To our knowledge, no social networking websites have been designed to build community, reduce social isolation, and create positive norms around HIV and other sexually transmitted infections (STI) for YBMSM. This study explored perceptions of social isolation and sense of community among YBMSM in order to inform an internet and mobile phone-based primary and secondary HIV prevention intervention.

Methods

Data Collection

The methods for this study have been previously described (Muessig et al., 2013). Briefly, three focus groups were conducted with 22 YBMSM in North Carolina (NC). To assess the need for and design of a community building component of an HIV intervention for YBMSM, focus group questions explored men's experiences of social isolation, existing outlets and challenges for social networking, and receptivity to using community building features through [intervention name]. The study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Focus group participants were recruited using targeted sampling at health centers, community-based venues (e.g. cafes, gyms), college campuses, and online (n=15). Eligible participants were also encouraged to refer friends resulting in 7 additional enrollees (Muessig, et al., 2013). Inclusion criteria was age 18 to 30, born biologically male, self-identify as black or African American, reside in NC, self-report lifetime sex with another man, and currently use a mobile device.

Focus groups led by a trained facilitator lasted approximately 90 minutes and were held with six to nine participants each. A research team member recorded non-verbal cues and the groups were digitally recorded and transcribed. Before the focus groups, participants provided informed consent and completed a brief demographic survey. Each participant chose a pseudonym for privacy and received a \$50 gift card for remuneration.

Data analysis

Demographic data were summarized using Microsoft Excel. A qualitative coding scheme was developed from the focus group guide and emergent themes. Two research team members coded each transcript using NVivo software (QSR International Pty Ltd, 2012). Discrepancies were resolved through team discussion. Key themes were generated and quotes chosen by group consensus to illustrate common responses and variation within each theme. Our primary findings are presented in two domains: (1) social isolation and lack of a sense of community and (2) the use of a website/phone app to build a sense of community, reduce social isolation and facilitate social networking.

Results

Demographics

Participants ranged in age from 20 to 30 years old (mean: 24 years) (Table 1). Half of participants earned less than \$11,000 per year. Half reported lifetime sex with men only; half with both men and women. All participants had access to the internet via laptops and/or mobile phones. Almost all (n=18) used applications "apps" on their phone on a daily basis and over one-third sent more than 100 text messages per day. Approximately 64% (n=14) used mobile phones to search for health information and half reported using their phones to find sex partners (includes any type of sex partner – e.g. casual, romantic, commercial).

Part I: Social isolation and lack of a sense of community

Feelings of social isolation and lack of a sense of community were pervasive. Homophobia, limited opportunities for socializing with other YBMSM, and a primary focus on sex within relationships rather than shared common interests were identified as contributing factors.

Homophobia—Participants discussed homophobia and secrecy around same sex behaviors as impacting social isolation and sense of community: It's [City X] period.

It's kind of small and there's still a lot of hate amongst a lot of people I run into towards gays...[isolation is] cause we're not talking. I guess they're scared or frightened or thinking about what the next person will say. (True K, age 30)

Another man noted that "people are more closeted here" (Andre, age 28), referring to gay men in NC as compared with other areas of the country, and connected this secrecy with an inability to socialize with other gay men in public. As discussed below, even men who connected with other YBMSM remained socially isolated from broader communities.

Limited opportunities for socializing with other YBMSM—Participants overwhelmingly reported a lack of a sense of community for YBMSM in their geographic area, in part because of limited opportunities for in-person socializing:

Not being able to go out and go to a bar and mix with people that have the same likes that I have, yeah it does make you isolated. (James, age 28)

There's not a lot of variety of options for the variety of people who are in this lifestyle or within our own community. When it comes to giving you something to do... down here there's two. That's it...There's not a lot of opportunity...to mingle and interact or at the very least just happen to run into each other. (Poet, age 24)

Limited social opportunities included an overall lack of places to socialize and a lack of variety within existing venues to accommodate diversity among YBMSM.

Sex as the focus of interpersonal relationships—Isolation was also driven by the perception that other men only wanted to engage in a relationship for sex. According to one participant:

I think really the thing that keeps us separate is the sexual stuff, like most of the time when you want to talk to someone that's gay they only want to do sexual stuff and if it's not about that then they don't want to talk to you. (Lamar, age 20)

Most men agreed that online social networking options for YBMSM (e.g. Facebook, Black Gay Chat [BGC]) contributed to this problem by allowing sexually graphic material. The focus on sex in existing social networking sites was viewed as a barrier to using these sites to build community:

I feel like a lot of sites, like BGC...try to let people know about events and things, but most sites are out there and available for black gay men are mostly just hookup sites. They all have good intentions, you know, start out with a sense of community, but it just kind of turns into just a hookup site. (Brad, age 22)

Part II: Use of a website to build a sense of community, reduce social isolation and facilitate social networking

Focus group participants supported the idea of building community via online mechanisms.

Perceived benefits of a social networking feature—Men described several potential benefits of social networking components within an HIV prevention website, including building community, reducing social isolation, and addressing depression:

If the website in some ways helps people to think through what building community actually means, and kind of how do we break down the barriers between ourselves...there's that potential there. (Andre, age 28)

People who feel isolated or something like that are – it would be a way for them to go into this website and look at stuff that's going on or look at things that's happening – 'I can go here and meet a couple people.' So I think it would be a way, a very helpful way, to reduce [social isolation]. (Shawn, age 23)

[This website could] cut down on a lot of depression and aggravation, frustration. (Brad, age 22)

Social networking needs and preferences—The most strongly endorsed features of a social networking component were facilitating communication with other YBMSM and health professionals, offering health information—especially around HIV testing, STI and drug/alcohol use—and promoting positive social norms around sex and men's health. Several participants described how an online social networking feature could facilitate communication around these issues:

A site that would have people here for us to open up and talk about issues that are bothering us. Where we can come together and, especially let us know about certain things that do need to happen and good things that can improve our life. (True K, age 30)

Many participants mentioned healthy relationships as a content area especially well-suited for a social networking feature. Healthy relationships were described as intimate relationships based on trust and mutual respect with an emphasis on communication within the relationship rather than a focus only on sex. Skills of interest included understanding relationships, building communication skills, and having safer sex in the context of relationships. Several men felt that they did not have these skills needed to initiate and maintain healthy relationships:

We haven't been taught those things. We weren't raised to know how to love another man or have a relationship with other men – or have community with other gay men –because that's just not the world that most of us come from. So helping us navigate those things and understand what they mean for us and our health. (Andre, age 28)

Other requested social networking content areas included support for dealing with the pressure of talking to parents about sexuality, examples of “coming out” stories, and experiences of others living with HIV. Participants noted that postings about places to travel,

gay-friendly employers and venues, and gay-sponsored events would also help build community. These types of postings were an important way to reduce isolation: “Because I don’t really talk to a lot of people out and about in the community so it’s kind of hard to get any information.” (Brad, age 22)

According to participants, an ideal social networking site would accommodate real-time chat with other participants: “To be able to chat with different people – not just like post on their wall or post on their profile, actually like an instant chat type of thing. That would be pretty cool” (Shawn, 23). There was also strong interest in using the social networking site to discuss HIV/STI test results, receive counseling, and take part in group information sessions (virtual and in-person) with health professionals and HIV-positive YBMSM.

Optimizing a social networking component—Participants recommended external facilitation in order to optimize the utility of social networking components. For example, one man felt that it would be helpful to have a member of the website management staff serve as a “social facilitator”:

I think that it’s incumbent on you all – especially in the beginning, to really make a huge effort to facilitate communication between people until that ice is broken to where they feel comfortable taking ownership and then building their own community. (Andre, age 28)

Many men expressed concern that the site would devolve into a “hook-up” site if left unmonitored. As such, there was widespread support for content oversight by website administrators. Specifically, participants recommended censoring user-posted pictures or prohibiting picture and video posting. Another participant discussed the importance of monitoring event boards, saying “well you have to monitor that- because the event board could mean sex parties, drug parties, whatever. So, you gotta be careful” (Cortez, age 28).

Discussion

The development of a social networking feature for an internet and mobile phone-based primary and secondary HIV prevention intervention offers opportunities to reduce social isolation, increase social support, and build a community that promotes healthy behaviors among YBMSM. Social networks can reduce social isolation and provide individuals with informational, emotional, and material support to facilitate and sustain behavior change (Cohen, 2004; S. D. Rhodes, 2004; Weinert, et al., 2011; Young, Szekeres, & Coates, 2013).

We used qualitative methods to understand perceptions of social isolation and sense of community among YBMSM in NC, receptivity to the use of social networking to address related needs, and specific preferences for adding a social networking component to an existing intervention. In this sample, feelings of social isolation and a lack of a sense of community were widespread. While negative attitudes about homosexuality in the US have decreased among whites over time, there has been little change in attitudes among blacks (Glick & Golden, 2010).

Few opportunities for social engagement with other YBMSM and a focus on sex in interpersonal relationships were identified as factors that contribute to social isolation and the absence of community. Limited opportunities to engage with other YBMSM in nonsexual contexts hinders building communities that support healthy lifestyles and behavioral norms. Similar requests for nonsexual social support were identified by participants in a study of a sexual risk reduction intervention conducted within an existing social and sexual networking chat room for MSM (S. D. Rhodes, 2004).

Including a social networking feature within HIV prevention interventions could provide a safe space for YBMSM to find peer support and information on sexuality, healthy relationships and sexual health. Users may feel more comfortable engaging in an online intervention that protects their anonymity while also connecting them to other geographical social circles.

Participants had clear recommendations for both the content and social networking options. Most importantly, men wanted features connecting them to other YBMSM and providing a virtual venue to openly discuss important issues—such as disclosing sexual identity or maintaining healthy relationships—and receive support from other YBMSM in real time. Peer support has long been recognized as an important component of interventions that promote healthy behaviors and behavior change, including those that are internet-based (Brouwer et al., 2011; Horvath et al., 2012; Young, Cumberland, et al., 2013).

Study participants strongly recommended that a social networking component offer opportunities to engage with health care professionals, in particular the ability to discuss positive HIV/STI test results. Access to a knowledgeable provider to discuss test results via a social networking website may help reduce fears around testing and improve treatment-seeking among individuals who test positive.

Participants felt that a social networking feature might be more successful if there was a study staff member monitoring site activity who could engage users and facilitate site activity. Hovarth et al. (2012) made a similar recommendation that future social networking sites designed for individuals living with HIV facilitate earlier interactions to foster group cohesion and create a supportive environment. Study participants also recommended monitoring to prevent devolution of a social networking site into a “hook-up” site. Given the heavy use of social networking sites to find sexual partners among YBMSM in this study (50%) and among MSM overall (Liau, Millett, & Marks, 2006), careful monitoring of site postings for inappropriate content is warranted.

The study has several limitations. For example, about one-third of participants were recruited via friend referral. As such, it is plausible that men who had more YBMSM friends were more likely to be recruited into the study. If our sample was biased in this way, our findings would likely underrepresent the intensity of social isolation and lack of a sense of community. Participants were provided a gift card to compensate them for their time. This may have encouraged a larger portion of men with lower incomes to participate in the study. The study is limited in generalizability in that it utilizes a small convenience sample of mobile phone-using YBMSM from three cities in NC and is unlikely to capture the full

variety of perspectives of all YBMSM living in the US. Nevertheless, we purposively recruited a diverse sample of YBMSM from numerous social venues, clinical sites, and cyber settings. Data from our pre-focus group survey showed that our participants were similar to other YBMSM study samples from NC (L. B. Hightow-Weidman, et al., 2012; L. B. Hightow-Weidman, Smith, Valera, Matthews, & Lyons, 2011; Hurt et al., 2010), representing a range of income/education, sexual self-identity, and utilization of the internet to find health information and sex partners.

Despite these limitations, the results of this study reflect findings from previous studies and provide new information about the need for and receptivity to including social networking features within online HIV prevention interventions for YBMSM.

Conclusion

The results of this study support further research to include and evaluate social networking components within online HIV prevention interventions for YBMSM. These features could be used to facilitate peer support based on shared information and experiences, establish positive behavioral norms around HIV prevention and care, and provide information and support from health care professionals. Moreover, the creation of a “virtual” community as part of an internet and mobile phone-based primary and secondary HIV prevention intervention for YBMSM who may lack a sense of belonging to MSM or black communities may reduce social isolation and support and normalize safer sex behaviors.

Acknowledgments

Sara LeGrand, Emily C. Pike, Nina Baltierra, and Lisa B. Hightow-Weidman are supported by the NIH (R01 MH093275-01). Kathryn E. Muessig was supported by an NIH institutional training grant (5T32AI007001-35).

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Table 1

Demographic and mobile phone use characteristics

	No (%) or mean (SD) N=22	
Mean age	24	3.0
Income		
<10,999	11	50.0
11,000–20,999	6	27.3
21,000–30,999	2	9.1
31,000–40,999	0	0.0
41,000–50,999	1	4.5
51,000	0	0.0
Prefer not to answer	2	9.1
Phone platform		
Android	15	68.2
Windows Mobile	3	13.6
Apple	2	9.1
Blackberry	2	9.1
Means typically access the internet ^a		
Mobile	14	63.6
Laptop	16	72.7
Desktop	1	4.5
iPad	1	4.5
Use apps on phone on daily basis		
Yes	18	81.8
No	1	4.5
Did not respond	3	13.6
Average number of texts sent on a daily basis		
0–9	1	4.5
10–49	7	31.8
50–99	5	22.7
100	8	36.4
Did not respond	1	4.5
Use phone to find sex partners	11	50.0
Use phone to search for health information	14	63.6
Use health/fitness related “app” on phone	2	9.1

^aSums to >22 because participants were allowed to choose more than one device