Published in final edited form as:

J Assoc Nurses AIDS Care. 2015 ; 26(4): 411–419. doi:10.1016/j.jana.2014.11.004.

HIV-infected women's perspectives on the use of the Internet for social support: A potential role for online group-based interventions

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Abstract

While the development and implementation of HIV-related online interventions has expanded, few have been tailored for women or have leveraged Web 2.0's capabilities to provide social support. We conducted semi-structured interviews with 27 women with HIV at an urban community health center to understand their perspectives on the potential role of the Internet and the use of an online group format to provide social support. Data were analyzed using the constant comparative method. We identified six themes: a need for groups and increased sense of connectedness, convenience and accessibility, trust as a precondition for participating, online groups as a potential facilitator or barrier to expression, limited digital access and literacy, and privacy concerns. Overall, women were highly supportive of online group-based interventions but acknowledged the need for increased digital access and Internet navigation training. Hybrid (in-person and online) interventions may be most useful for women with HIV.

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Disclosures

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

Keywords

HIV; Internet; intervention; online; women

Group-based health interventions are a common approach to leverage social support and increase motivation for positive behavior change (Campbell et al., 2000). Such interventions can directly buffer potentially distressing effects of an HIV diagnosis or a related medical condition (e.g., substance use disorder). HIV-related group interventions have been associated with decreased shame, HIV-related stigma, and risk behaviors, and increased perceived social support (Hyde, Appleby, Weiss, Bailey, & Morgan, 2005; Lennon-Dearing, 2008). Group-based interventions may be especially useful for women with HIV, as studies have demonstrated that they often lack positive social support (Hosek, Brothers, & Lemos, 2012; Squires et al., 2011; Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012), and many do not seek support within their existing social networks (Wingood et al., 2004). Providing women greater access to group-based interventions to address these important gaps may improve overall wellbeing and adjustment to living with HIV.

Technology-delivered interventions have proliferated in the past decade, with some showing positive effects on the health and wellbeing of people with HIV (Pellowski & Kalichman, 2012). A variety of different devices (e.g., computer, mobile, tablet) now are available to deliver health interventions and most have the ability to access the Internet. As such, online interventions may be easily disseminated to people with HIV, including women. Research has found that some women with HIV go online seeking support, but they often struggle to find such support (Walsh et al., 2012). To complicate matters, women with HIV are disproportionately African American or Latina and overwhelmingly socioeconomically disadvantaged, factors that are associated with lower rates of Internet use (Zickuhr & Smith, 2012). These challenges may, in part, explain why most HIV-related online interventions have been tailored for men who have sex with men (MSM) or adolescents (Bull, Levine, Black, Schmiede, & Santelli, 2012; Danielson et al., 2013; Hightow-Weidman et al., 2012; Hirshfield et al., 2012; Horvath et al., 2013; Rosser et al., 2010; Young et al., 2013).

Even though peer support is a recommended strategy to improve HIV outcomes (Thompson et al., 2012), relatively few Internet-based HIV interventions leverage peer-to-peer social support that has come to characterize Web 2.0 technology. Online chat room-based interventions that allow participants to exchange information and share experiences have been shown to increase social support (Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). Horvath et al. (2013) pilot tested a peer-to-peer support intervention to improve antiretroviral therapy adherence outcomes in MSM. To our knowledge, there is only one group-based video conferencing intervention for women with HIV (Marhefka et al., 2013). Taken together, existing research shows great promise for the use of online group-based interventions to improve HIV outcomes for women, but more information is needed to optimize reach and potential impact.

To address this gap in the literature, we interviewed women with HIV to gain a greater understanding of their perspectives on the potential role of the Internet to address their health needs. In particular, we were interested in gathering more information about what

women perceived to be opportunities and challenges to implementing an online group-based intervention to increase social support. Our findings will help inform development of interventions that use the Internet, and possibly other forms of technologies, to improve the health and wellbeing of women with HIV.

Methods

Setting

Our study was conducted at a community-based clinic in the Bronx, NY, which provides general and HIV primary care. The clinic mostly serves surrounding communities that are predominantly African American/Black and Latino and have high rates of poverty and chronic diseases, including HIV infection (New York City Department of Health and Mental Hygiene, 2010).

Participants

We recruited patients from February to June 2013 who were: (a) female, (b) at least 18 years of age, (c) HIV infected, and (d) English proficient. We approached patients in the clinic waiting room and contacted patients who had previously expressed interest in participating in ongoing research studies. Participants provided written informed consent and were reimbursed 20 USD and travel expenses for their time (approximately 4.50 USD). The Albert Einstein College of Medicine Institutional Review Board approved the study.

Data Collection

A trained female research assistant conducted semi-structured individual interviews lasting 45 to 90 minutes in a private clinic room. Interviews elicited women's beliefs about, and personal experiences with, the Internet. We were particularly interested in understanding their perceptions about the use of an online group format to provide social support for themselves and other women with HIV. As such, we asked participants to reflect on a hypothetical online peer-to-peer social support group that had the following features: participant-driven, targeted women with HIV who were patients at the clinic, accessible any time of day, allowed messages of support or encouragement to one another to be posted, and allowed for questioning about living with HIV and taking HIV medications. Women reflected on their perceptions of an online-only group compared to an online group as a supplement to an in-person clinic-based group. Interviews were audiotaped and professionally transcribed.

Analysis

We used Nvivo 10 software (QSR International) to organize data and facilitate data retrieval. Consistent with grounded theory (Strauss & Corbin, 1990), we coded data in stages and used systematic inductive methods to identify emergent themes. A team of three coders analyzed data independently. First, we conducted open coding, which involved reading the transcripts several times and identifying broad emergent concepts. Next, we used selective coding to focus coding on the most relevant and important concepts. We resolved discrepancies in coding through discussion. We used the constant comparative method

throughout this process to ensure that codes were applied consistently (Strauss & Corbin, 1990); we expanded and refined as needed.

Results

Participant Characteristics

Of 32 eligible women approached, 27 (84%) enrolled. On average, women were 48 (48.7 ± 8.8) years of age, and the median time since HIV diagnosis was 17 years (interquartile range: 13.5–20.5). Fifteen (55%) self-identified as Hispanic and 12 (45%) as non-Hispanic Black. Twenty-six women (96%) owned a cellphone and 20 (74%) had Internet access either at home and/or on their cellphones. Twenty-two (82%) had previously used the Internet and 20 (74%) had used social media. Twenty-six (96%) had participated in an in-person group at a health care setting.

Themes

We identified the following six themes: (a) the need for groups and increased sense of connectedness, (b) convenience and accessibility, (c) trust as a precondition for participating, (d) online groups as a potential facilitator or barrier to expression, (e) limited digital access and digital literacy, and (f) privacy concerns. Each of these is described in greater detail below.

Need for groups and increased sense of connectedness—Many women reported a lack of social support and feeling isolated and, as a result, a desire to connect with other HIV-infected women like themselves. They shared the perception that having opportunities to come together in groups, whether in person or online, would have the potential to increase feelings of connectedness to others, as well as to provide a venue for much needed social support. When asked specifically about the benefits of an online group, women believed that it would help facilitate exchange of important health-related information and provide support for socially isolated HIV-infected women. For example, a 52-year-old woman with prior experience with groups and minimal familial support stated:

A lot of women with HIV don't have support or they keep [issues] to themselves because there's nobody. They feel like me; they can't trust anybody or they think others just won't understand. So getting [interaction] online, it's just more support. Groups may help because you may link up and find a friend, a partner where you all could talk about different issues, especially for women of color. We get so many different problems.

Additionally, because many women had already had experience with in-person support groups, they perceived online group opportunities as a complement to existing in-person groups. A 42-year-old woman who regularly used the Internet stated:

Having a regular group that then extends to the Internet is good because even when you're home, if you have an issue, you can type it in. Then, when you all meet each other, you can talk about it. [Without an online group], by the time you come to the [in-person] group, you forget what you wanted to talk about. You might get the feedback you need on the Internet or in the next group.

However, although the desire for groups and peer support was common, some participants noted that age might influence which format (in-person vs. online) would be more appealing to women. A minority of women, most of whom were older (i.e., 40 years and older), perceived the Internet and Internet-related activities as appealing to only younger women and, therefore, were less interested in participating in an online group and preferred in-person groups. A 39-year-old woman who participated frequently in in-person groups and who had minimal Internet experience commented:

I think for younger women who are already doing it, that's for them. But for older women - I'm not saying I'm old – but, I'm at an age where I'm comfortable with what I have and I think it's better in a [in-person] group setting. When it's younger people, [an online group] is for them.

Despite this, most older women with Internet experience viewed an online group favorably.

Enhanced convenience and accessibility—Online groups were perceived by women as being convenient and increasing accessibility to information and social support. Some women felt they could use the online group to get information when their health care providers were not available. Others stated that an online group would enable women to participate without having to leave home and at times most convenient to them. For example, a 48-year-old woman noted: “It's being there without being there and still being in the comfort of your own home. I'm a home person. So, [an online group] is being connected with others and not having to leave home.”

Participants believed that an online group would provide an advantage for women with more advanced disease and were not able to leave home due to their disabilities. A 52-year-old woman who lived in a residential facility for people with HIV, and who had never used the Internet, commented: “It might be an advantage to people who is really, really sick, and they can't get out. The online group may be another option for them.”

The asynchronous nature of online groups (i.e., posting whenever it is convenient as opposed to at a set time during which all group members could converse) was highlighted as a positive feature as it could make participation more convenient. For example, a 42-year-old woman who was a frequent Internet and social media user stated: “It will help because you have more time to get on the computer. You can get on the computer anytime and it won't be just that 1 week, that 1 day a week, or whenever the [in-person] group is.”

Trust as a precondition to participating—Another recurrent theme was that of trust between group members. Many women noted how they had contracted HIV from a partner they had trusted. Therefore, having a sound foundation of trust in one's relationships was crucially important, whether the relationship was in person or online. Women preferred to correspond online with other women they knew and with whom they believed confidentiality would be maintained. Many women viewed trust as a necessary precondition for interacting with others in an online group. For example, a 57-year-old woman who often used Facebook® shared:

There's a positive aspect of being able to form an online group full of women that communicate with each other about issues pertaining to their health. I still would just be a little leery of discussing specific things on the Internet right now until I can get a sense of being able to trust them...being secure in the knowledge that what we were talking about wasn't going to go any further.

Several women suggested that trust could be nurtured initially through interactions in an in-person group, during which time relationships could first be established. In-person interactions were perceived as the primary mode for developing trust. A 53-year-old woman who said she distrusted the Internet, but who was interested in meeting other HIV-infected women for support stated: "I would want to meet the person in person first, so that we could build that closeness."

Online groups as a potential facilitator or barrier to expression—Women expressed ambivalence about how an online group might affect the quality of interaction among group members. Some viewed an online group as providing a protective emotional buffer for women who might feel shy or anxious about speaking in front of others, allowing them to more freely express themselves. Similarly, some felt that the potential anonymity provided by an online-only group might facilitate open and candid discussions. A 58-year-old woman who experienced alienation and judgment from others while participating in in-person groups noted:

They would be able to just say things that they don't dare say to other people or people in front of them. They would be able to open up more. Some people don't want to say things in front of other people.

At the same time, there was also acknowledgement of the benefits of being physically in the presence of others, such as being able to see each other's reactions or to be able to provide touch as a demonstration of support. In this way, the online group was viewed as a potential barrier to perceiving others' emotions and, therefore, reducing the quality of interaction. For instance, a 42-year-old woman who frequently used the Internet, including social media, for health-related information shared:

I feel other people more when I see their reaction; when you're there with them, you feel them. Like if somebody is saying something on the computer, you're not seeing their reaction. You don't know if they're ready to cry. On the computer, you're not going to get the feeling that much.

Limited digital access and literacy—In contrast to the previous themes that were more specific to women's perceptions of online groups, participants also voiced concerns about the Internet more generally. For instance, although most women reported Internet access and having used the Internet and social media, some worried about whether other women like themselves would have Internet access or be able to effectively navigate the Internet (i.e., digital literacy). Limited digital access and literacy were perceived as potential barriers to online group participation. A 47-year-old woman who used Facebook® frequently worried that other women might not have access to a computer: "There are people that have a

computer, but there's also some people that don't have computer. They gotta' go to libraries or somewhere [to find a computer]."

Several women who had not used the Internet expressed concern that they would be unable to participate in an online group because they did not know how to use the Internet or social media. For example, a 52-year-old woman who expressed concern about sharing her information on the Internet and who had no Internet experience shared: "I don't know how to play with the Internet. I just don't know. Maybe if I had the ability to do so I would, but I just don't know."

General Internet privacy concerns—Another general concern about the Internet that women expressed related to privacy. Worries about privacy were not rooted in women's concerns about others finding out about their HIV status. Rather, women were concerned about others who they did not know intruding in or silently monitoring their online discussions and obtaining their personal information, such as their names or social security numbers. For instance, a 46-year-old woman who used the Internet and social media on her cellphone for networking and job-related publicity commented: "I would feel a little insecure [using an online group] because you might have some great old computer whiz that can look at your computer address and find out who that actually belongs to."

Discussion

In this study, we sought to understand women's perspectives about the potential of the Internet to generally address their health and wellbeing needs and, specifically, as a platform to deliver an online peer-to-peer social support group. We anticipate these findings will help inform the development of Internet-based interventions seeking to enhance social support for women with HIV. Our study identified both potential benefits and challenges regarding using the Internet and, specifically, an online group format, to increase social support among women with HIV. Potential benefits included offering women an increased sense of connectedness and emotional support, while challenges included concerns related to trust as well as digital access and literacy.

Women in our study viewed the Internet, in general, and an online peer-to-peer support group, specifically, as viable ways to increase feelings of connectedness and obtain emotional and social support for themselves and other women with HIV. Consistent with previous research, because participants reported feeling socially isolated, they perceived a need for group-based interventions (Lennon-Dearing, 2008; Walsh et al., 2012). Overall, women expressed enthusiasm for, and interest in, the potential to interact online with others like themselves. In addition to social support, most participants felt an online group would offer a convenient way to access health-related information.

Women also appreciated that, for some, the anonymity that the Internet provided might result in more candid discussions among peers. However, participants also stated that knowing and developing trust between group members was critical to the success of such groups. This finding highlighted the importance of understanding the particular group norms of persons who are being reached with an intervention. While conversing with previously

unknown others may be normative for certain groups of people, such as MSM (Bull, McFarlane, & King, 2001), completely anonymous online peer-to-peer support groups may not be desirable for women with HIV. Trust between women may be nurtured by first meeting in person until group cohesion is fostered, followed by the introduction of an online group component. A review of interventions to promote weight loss found that Internet-based interventions that only provided an information resource may be better as online-only interventions while other types of interventions (e.g., those seeking to enhance social support) may require both face-to-face and online components (Norman et al., 2007). A systematic review found that antiretroviral adherence interventions that combined technology with face-to-face components performed better than technology alone, implying an important role for in-person interactions in the context of technology-assisted interventions (Saber & Johnson, 2011). A combined intervention approach for women with HIV that includes both in-person and virtual components should be explored in future intervention studies.

Limited Internet access and digital literacy were raised as potential barriers to the implementation of an online social support group. Concerns about Internet access and digital literacy reflect the challenges that women with HIV, many with limited socioeconomic resources, face in getting online and navigating the Internet. Limited Internet access has been associated with lower rates of Internet use among persons living with HIV (Thomas & Shuter, 2010) and appears to continue to be a concern in this sample of women. Despite continued disparities in Internet access (Zickuhr & Smith, 2012), other data indicate that these barriers may be decreasing as a result of mobile device ownership (Pew Research Internet Project, 2014). Lack of or limited Internet access may be addressed by providing participants with information about locations where free computer and Internet access are available, such as libraries and community-based organizations (CBOs). Many CBOs, particularly AIDS service organizations, view providing access to the Internet and similar technology as part of their mission (Benotsch et al., 2006). Additionally, HIV clinics could provide Wi-Fi access as well as tablets and computers for patients to use.

Digital literacy is a relatively newer concept and has received less attention than digital access. To address limited digital literacy, training in the use of the Internet can be integrated into the intervention itself. Training may include ways to maximize privacy online (e.g., using pseudonyms and deleting cookies). Two studies of interventions to enhance Internet-navigating skills among persons with HIV or Hepatitis C showed promising results (Kalichman et al., 2006; McInnes et al., 2013). One study involving patients with HIV or Hepatitis C found four 2-hour group computer and Internet training sessions increased Internet use and self-efficacy (McInnes et al., 2013). Another study of an intervention designed to improve skills for locating and evaluating relevant health information online demonstrated increased Internet use for health, information coping, and social support (Kalichman et al., 2006). Conducting usability testing to ensure that online intervention components are easily navigable for persons with low literacy may be an essential component for technology-delivered interventions for women with HIV. These steps could also help to address some participants' concerns that Internet-based interventions may not be appropriate for older women with minimal Internet experience.

Our study has several limitations. Participants were asked to reflect on their own Internet-related experiences and a hypothetical online peer-to-peer support group, rather than providing feedback on an ongoing online group intervention. Although women's feedback may have differed if they had actually taken part in such an intervention, these findings will allow us to improve the feasibility and acceptability of implementing future interventions tailored to women with HIV that leverage the Internet or online group formats. Second, the study included only women from the Bronx, New York. It is possible that women with HIV in other regions may have different beliefs and perceptions about online groups. Third, we interviewed only women who were in HIV care and may have missed more marginalized women without access to the Internet or other forms of technology. Therefore, these findings may not apply to women who are not in HIV care.

Conclusions

Overall, women in our study expressed support for connecting with other women with HIV via the Internet generally and, specifically, as part of an online peer-to-peer support group. Women also acknowledged potential challenges related to trust, digital access and literacy, and privacy that may need to be addressed to increase the potential reach of Internet-based interventions. Our findings support the use of a hybrid in-person and online group-based intervention, which may be enhanced by increasing online access for women and integrating training in digital literacy and privacy. We believe these findings will help to inform the development of interventions for women with HIV who seek to use the Internet to foster social support to improve their overall health and wellbeing.

Acknowledgements

This study was supported by NIH K23MH102129, K24DA036955, NIH R25DA023021, and the Center for AIDS Research at the Albert Einstein College of Medicine and Montefiore Medical Center (NIH AI-51519). The funding source had no role in the study design; the collection, analysis, and interpretation of data; writing of the report; or decision to submit the article for publication. The authors thank the members of the Montefiore-Einstein Division of General Internal Medicine Qualitative Research Affinity Group for their thoughtful feedback on the study design, analysis, and manuscript.

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Key Considerations

- As there remains a substantial need for social support among women with HIV, health care providers should regularly assess patients' existing social support resources and refer patients to women's support groups and to online support resources as needed.
- Clinical sites and community-based organizations (CBOs) providing care or services to women with HIV may benefit from providing free Internet and/or computer access to help women identify relevant health-related information and support resources.
- Similarly, CBOs that provide care or services to women with HIV should offer training in how to navigate the Internet to find relevant health and support resources.