

What HIV-Positive Young Women Want from Behavioral Interventions: A Qualitative Approach

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Abstract

Young women living with HIV in the United States face many social and psychological challenges, including involvement in health care and secondary prevention efforts. The factors that put these young women at risk for HIV acquisition initially, such as poverty, gender roles, cultural norms, and limited perceived control over sexual relationships, continue to place them at risk for both adverse mental and physical health outcomes that impact their daily lives and secondary prevention efforts. This study utilized focus groups with young HIV-positive women in order to better understand their perceived problems and pressures and to inform a developmentally appropriate secondary prevention intervention for young HIV-positive women that could be implemented in clinical care settings. Focus groups with young HIV-positive women were convened in three U.S. cities: Baltimore, Chicago, and Tampa. A total of 17 young, HIV-positive women, age range 17–24 (mean age=21), participated in the focus groups. This article describes the psychological and social challenges these young women face as well as their suggestions regarding secondary HIV prevention intervention components.

Introduction

WOMEN IN THE UNITED STATES account for more than one quarter of new HIV/AIDS diagnoses today.¹ Most women with AIDS were diagnosed between the ages of 25–44, indicating that many were likely infected at a relatively young age.² The impact on teen girls is particularly notable. In 2004, teen girls in the United States represented 43% of AIDS cases among those aged 13–19, and young women aged 20–24 represented 33% of AIDS cases in their respective age group.² Women of color, particularly African American women, are disproportionately impacted by HIV/AIDS. African American women account for 67% of AIDS cases among women, but only 12% of the U.S. population of women.¹ Latinas account for 16% of estimated AIDS cases, compared to comprising 13% of the female population.¹ Thus it is important that researchers understand the perceived needs of this population as they make up a significant portion of the HIV positive population.

In addition to the primary prevention needs of young women, there is also a great need for secondary prevention efforts that empower HIV-positive youth to decrease risky sexual and drug use behaviors that place them at risk for HIV reinfection and transmission to their uninfected partners (i.e., prevention for positives).³ Traditional secondary prevention approaches include the promotion of abstinence, partner re-

duction, consistent condom use, disclosure, and use of clean injection equipment.³ However there is limited literature on how best to promote secondary prevention among young HIV-positive women.^{3–9}

While there have been no published secondary prevention interventions solely targeting young HIV-positive women to date, there are known social, relational, and personal factors that have the ability to act as a facilitators or barriers to HIV prevention efforts. Common social and psychological challenges such as poverty, limited access to care, gender roles, cultural norms, and limited perceived control over sexual relationships not only impact the daily lives of young, HIV-positive women in the United States but they also are known to decrease their involvement in secondary prevention efforts.^{3–9} For example if violence, victimization, and poor mental health, which have been found to be pervasive among young HIV-positive youth,^{10,11} are left untreated or unacknowledged, then risk factors, such as substance abuse, unsafe sexual activity, and nonadherence can increase. Likewise, relationships both sexual and nonsexual, influence the health and well-being of young HIV-positive women.^{5–9,12} Perceived social support from family and peers has been linked to mental health, risk behavior, medication adherence, and disclosure of one's status among HIV-positive adults.^{13–21} Another relationship dynamic that has been correlated with HIV risk behavior is relationship power. For women, condom use

requires the participation and/or cooperation of their partners.^{22,23} Thus, the power-holder in the relationship becomes an important influence for condom use. In fact, several studies have shown an association between women having power in a relationship and the increased likelihood that condoms will be used.^{5-9,12,24,25} Finally, stigma, low self-esteem, and decreased self-worth can impact the mental health and decision making processes of young women for both risk and health seeking behaviors, such as disclosure and adherence to medication, especially among those who are living with HIV.^{13,20,21,26-33}

Addressing these social, relational, and personal factors is vital in order for secondary prevention efforts to succeed. It remains unclear, however, how best to address these factors with young HIV-positive women due to the lack of targeted programs and research for this population.⁴⁻⁹ Therefore, eliciting input from young HIV-positive women regarding their perceived problems and pressures, including factors such as gender, violence, victimization, mental health, relationships, and stigma is critical in order to design developmentally appropriate and gender-specific interventions that meet their needs.

The goal of this article is to describe the findings from a qualitative study that involved young HIV-positive women in order to cultivate a developmentally and content pertinent intervention that would accurately address the psychological and social concerns that impact their lives.

Methods

Overview

This study was funded by the Adolescent Medicine Trials Network (ATN) for HIV/AIDS Interventions (ATN 073). Focus groups of young HIV-positive women were convened at three ATN sites: Chicago, Baltimore, and Tampa.

Focus group participants

A total of 17 HIV-positive young women ages 17-24 (mean age=21) participated in the focus groups. Three were perinatally infected with HIV while 14 had acquired HIV behaviorally. The majority of the young women identified as African American (88%). To be eligible for the study the women had to be between the ages of 16 and 24, receive services at one of the selected ATN sites or their community partners, and have documented HIV-infection.

Focus group procedures

The focus group interview guide was informed by the Theory of Gender and Power,³⁴ which explores sexual inequality, gender and power imbalances, and has been applied directly toward examination of the properties that increase women's vulnerability to HIV.⁸ The young women were first asked to discuss the life circumstances, challenges, and concerns young women living with HIV face and how those issues affect their ability to engage in safer sex behaviors and lead healthier lives. The participants were then asked to identify critical components for programs targeting young women living with HIV.

The structure of the focus groups utilized the "Rapid Approach" as identified by Krueger and Casey.³⁵ This approach differs from traditional focus groups because it asks fewer questions and tightly focuses on specific areas of inquiry. In-

formation regarding intervention content areas and representative activities were recorded on flip charts to capture and easily display participants' comments. Oral summaries were given back to participants at the end of each group, with the help of the facilitator to provide verification of predominant themes.

Potential participants were contacted by research staff at each of the ATN sites, either during regular clinic visits or by phone, and informed about the study. If the potential participant was interested, the participant was given an appointment to confirm eligibility, obtain informed consent, and collect contact information. Each focus group took place in a private space, was conducted in English, and lasted about 4 hours. The focus group facilitators were both female, MPH-level project directors with previous experience facilitating focus groups with youth. Token compensation, determined by each site's Institutional Review Board, and transportation vouchers were provided to participants to defray costs associated with time and travel.

Analysis

All focus group sessions were digitally recorded and then transcribed to allow for thematic analysis of the material. First, the transcripts were reviewed for accuracy. Second, members of the research team generated executive summaries of the focus groups based on review and integration of data from: (1) focus group flip charts, (2) audiotaped comments from participants, (3) audiotaped oral summaries by facilitators offered during the focus groups, and (4) thematic notes taken by the facilitator during the focus groups. Finally, the executive summaries were reviewed to identify themes across focus groups and to explore the proposed content and structure of the intervention.

Results

Challenges and concerns for young women living with HIV

Self-esteem. The participants reported varying levels of self-confidence, self-esteem, and self-worth. While some reported that they had high self-esteem and that HIV had very little impact on their goals and dreams, others talked of how being diagnosed with HIV had changed how they saw and felt about themselves.

There was also evidence that young women changed their interactions with others that were HIV-negative because their self-worth and perceived value in the community was less than that of someone who was "negative."

I would always, at first I would always feel like I would have to show them [friends and sexual partners], because of my status, I would have to show them, because he would feel like, even though if he didn't know what I had, I always felt I had to prove myself or that person won't accept me. (Chicago)

Just because of the fact that they have HIV. They [other people in the community] might think, just because they have HIV that they're not worth as much as they were before. (Tampa)

Because we, in most people eyes we'll be considered as nasty or not, dirty or whatever. (Tampa)

HIV disclosure. The participants acknowledged that disclosure of their HIV status was a lifelong process and the decision to disclosure was difficult.

It's hard to tell people that, it's hard to figure out who should you tell and who shouldn't you tell. Like I should tell my boyfriend, but it doesn't matter if I tell my mom or not. (Tampa)

While a few participants had disclosed their HIV status to their sexual partners and significant others, there were many who had not disclosed. The young women spent considerable time talking about the difficulties associated with "not exactly lying to them, but you just haven't told the big secret of your life." A common theme for not disclosing was the lack of trust in these relationships since previous disclosure experiences that resulted in negative judgment or rejection.

How can you keep a positive mind when the people you trust, like the people you think that are NOT gonna throw it in your face always come at you with it. Like your mother and your brothers and stuff like that. How can you keep a positive mind? (Tampa)

The participants talked about the emotional abuse they endured from their significant others including sexual partners, friends and family members after they disclosed their HIV status. The young women would often describe abusive environments including "throwing it in their face" or "putting them down" whenever they were involved in any arguments.

When they get mad they'll [family] throw it in my face, oh, you got HIV and all this other stuff. Like putting me down. That hurts bad. And they know it hurts, so that's why I think they throw it in my face. (Tampa)

Rejection and lack of support. Many of the young women shared very personal experiences of rejection from family, friends, and significant others with the majority of young women reporting little to no support from loved ones. This rejection and lack of support greatly impacted their daily lives as well as their future goals and relationships. Young women talked to a great extent about dealing with rejection from their own families, including their mothers, or significant others and the emotional toll it has on their lives.

I feel that nobody, I just don't have nobody. I don't have my momma, I don't have my daddy, I have a sister sometimes, but they got kids of they own, too. They can't tend to me like I want to, so I just try my best every day. (Chicago)

So she [mother] made me eat off paper plates and forks, I really stopped going over there, though. The only reason now is for the baby. Sometimes she rush us out of the house like she don't want us around, so I'm like, well, I see you when I see you. (Baltimore)

Some of the participants reported staying with the man that infected them because they were afraid of being rejected by someone else, while others admitted to closing themselves off to relationships for fear of rejection.

I don't have a relationship with anyone since I found out. I do still have sex with my daughter's father, but with a condom, because I'm too afraid of being rejected from someone else. So even with someone who's trying to talk to me, I just, I turn away, I don't want to talk. (Tampa)

Condom negotiation. The participants estimated that somewhere between "60%–70%" of sexual acts among them and their friends were unprotected and reported multiple

barriers to practicing safer sex, including lack of communication and education regarding other sexually transmitted infections, and lack of access to condoms during sex. The young women cited getting "caught up in the moment" as one of the main reasons for not using a condom.

I think it's like people, they just do what they want to do at that time and they don't think about condom at that time....You just want to do this thing right now. I just want to prove that I'm sexy. (Chicago)

Another barrier identified by participants was the struggle to negotiate condom use with partners that were aware of their HIV status but insisted on unprotected sex. Some participants reported that their sexual partner was responsible for his decisions.

I would see that they're promiscuous or really scandalous or whatever and I wouldn't feel sorry for them for not having, for not using protection, because I feel like, well, that at the route you're going, you're gonna catch what I have anyway. (Tampa)

However, many of the young women struggled with the guilt and anxiety of potentially infecting another person.

My guy is kind of weird. He's like I'm gonna get it. So let's not use a condom. I'm like NO! He's like, it's not a death sentence. I'd just have to take medication, so let's fuck without a condom. (Baltimore)

Critical components for interventions for young HIV-positive women

Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV-specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self-confidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships.

My perfect program wouldn't just not only be focused on the infection. It would just really be building self-worth, building self-esteem like all the way around. So many youth have a hard time just making that transition perhaps to the college, and still be like do they have to take care of themselves, either by nutrition, I mean, like my program, it was just, I couldn't, I could just say it. I would do it. (Chicago)

The participants desired program facilitators or interventionists that could "understand what I'm going through" and empathize or "sympathize" with them. Inherent in this empathic relationship was the need for the program facilitators to build and earn the young women's trust. Beyond these qualities, facilitators or peers should challenge the young women to extend beyond their comfort zones.

It will help give them that extra push, like say, yeah, take them by their hand, walk them to where they need to be and maybe they need you to be there just that much to get them to start doing what they need to do. (Baltimore)

For program structure, the participants reported preferring a combination of individual and group meetings. The group meetings would promote social bonding and young women "might even get some friendships out of it." Through the

combination of interactive activities, icebreakers, and discussions, the young women could “meet other people who are just like you,” which would help them realize that they are not alone. The individual sessions would allow women to “get things off their chest” and provide in-depth discussions with a counselor or therapist. In addition, participants reported that programs should have opportunities for young women to learn something positive about themselves, as one young woman stated: “Tell them something about themselves that they may not see, but what you see in them.”

Empowerment. Participants discussed the need for interventions that empowered young women not only through education, but by learning to support, accept and value themselves.

Where do you think that they should get those kind of resources from? Where do you think people should get those skills? [Facilitator]

It can be up to you how. The first thing I can say, like I should say, realize what is it. Like when you know WHAT is it, then accept yourself first before you want other people to accept you. Then once you just tell yourself, okay, this is what I have, and this is me, and there’s nothing wrong about me. It’s just the HIV, and if you think HIV is living you, and living with it, so that’s another problem. You don’t have to just, so okay, I have HIV, I cannot go to school, I cannot do this, I cannot do that. You can still be a doctor while you’re HIV positive. You can still do everything. So that’s the thing, I mean, I think you have to accept yourself. (Chicago)

Yeah, you have that [HIV] and at the same time you have to learn to support yourself. Then like as we talk about reject, you think like everybody gonna reject you and you think like, okay, this is the end of the world. I cannot do anything. You have to learn to help yourself, give self-esteem to yourself, and be YOU. (Chicago)

The participants suggested ways of incorporating empowerment principles into a secondary prevention that included building their self confidence by teaching life-skills and decision-making skills to empower young women to thrive in their community and live out their dreams. Some participants also emphasized the importance of building self-esteem to help them become leaders in their communities rather than followers.

Confidence, teach her how to be in society. Teach her how to thrive in, survive on her own in the real world, not just dealing with her own issues but how to deal with career goals, how to market yourself, how to just put yourself out there. (Chicago)

I mean, just teach them about decision making. It ain’t necessarily wrong crowd, right crowd, but if you become your own individual and you learn how to be a leader and not a follower, you can hang with people who doing what they doing. (Baltimore)

Identifying and choosing positive role models were reported as necessary steps for young women to become empowered and to dream of a better life for themselves. The participants tended to discuss entertainment related role models as important for career success. However, young women also discussed the need positive role models living with HIV.

Ask them who their role models are. They could be somebody famous or something like that. Be like, you see how they work hard to get that, you want to do that for yourself. You want that life for yourself. (Baltimore)

Sexuality education. The participants strongly emphasized the need for sexuality education that extends beyond “just bringing no babies home.” They suggested that interventions should focus on re-exposure to HIV, sexually transmitted infections and their consequences, teaching women how to use female condoms, and preparing them for condom negotiation.

The participants also reported that interventions developed for young women living with HIV should devote time to disclosure. Specifically, teaching young women “how to disclose and who to tell” by improving communication and learning to evaluate the risks and benefits of disclosure to others. Young women asked for activities that would help women to “stop and think” before they engage in sex with a partner of any type. Beyond teaching disclosure skills, these young women emphasized the need to deal with the emotions associated with disclosure such as rejection and judgment from others.

How to deal with a rejection. It doesn’t mean that because I told my friend that I’m HIV positive she’s gonna accept me. It doesn’t mean that because I told her I have to accept that she has to accept me. She can just OH, she gone. She’s out of my picture. So how do we deal with it...(Chicago)

Coping skills. In addition to building skills on how to cope with daily stress and pressures, participants requested that interventions provide tools for how to handle emotional situations and provide healthy coping options.

Maybe this program you could put, make up flash cards and put like pressures, stressors, what you could do if this come up and what you could do if that come up. Like all of this stuff. You could make cards up so the girls would say, if this come up, this is what you could do. Give them tips. Like they say, for stress is yoga. Just different, introducing young women and young people to different ways of dealing with stress. It’s not just talking about all the time issues, really having that time to yourself, to calm yourself down, think about what’s going on, what you need to do and then addressing it at that time. (Chicago)

I think a good way is helping young women how like to let go of stressors.....It’s not just getting over it, not holding it on and wearing it on your sleeve all day and let it impact school or work or home relationships or whatever and just dealing with it at that point. How to make it better. How to be real and just let it go. (Chicago)

Virtually all of the participants acknowledged that young women will inevitably continue to face disappointment, rejection and lack of support, but that an intervention could provide young women with the knowledge and skills they needed to better handle those situations when they arise. They also stressed the need for young women to believe in themselves and pursue their dreams.

Take your time. You got your whole life ahead of you. Do this and do that. Make sure that they stick with their goals and stuff that they want to be. (Baltimore)

Discussion

While there are a few secondary prevention interventions available at this time, there is no published secondary prevention intervention specifically targeting HIV-positive

young women. This qualitative study found that young women living with HIV face tremendous challenges that extend far beyond the content of typical risk-reduction interventions and that a comprehensive gender-responsive intervention that addresses the psychological and social issues that impact young HIV-positive women is warranted.

The young women in this study reported varying levels of self-esteem. While many declared that HIV should not impact one's future plans, most not only acknowledged the pervasiveness of HIV stigma in their communities but how some young HIV-positive women may put themselves at greater risk and/or tolerate unhealthy or less than ideal relationships with friends, family and sexual partners due to their lesser perceived value in the community. Many described unhealthy and unsupportive relationships with friends, family and romantic partners yet lacked effective communication and relationship skills and coping strategies to protect themselves especially when it came to knowing when to disclose their HIV status or when and how to "keep the secret." Unprotected sex was prevalent among these young women and the act of condom negotiation was usually met with apprehension, despite feelings of guilt over the possibility of infecting someone else.

While many of the challenges and concerns identified in this study are similar to other studies of young, HIV-positive populations (i.e., challenges with self esteem, HIV disclosure, rejection and lack of support and condom negotiation)^{36–39} the findings are unique in that the target population directly informed future intervention content and requested an intervention that is multidimensional, comprehensive, and tailored to their gender and age.

HIV/AIDS does not just impact physical health, but rather it can influence all aspects of life. The young women in this study confirmed that effective prevention and treatment interventions for young HIV-positive women must extend beyond HIV specific activities and incorporate a gender-specific comprehensive framework that works toward empowering young women sexually, emotionally, physically and socially so that they may lead happier and healthier lives while reducing HIV transmission.^{3,4,9,24,25,40} Secondary prevention interventions for young HIV-positive women should foster meaning, confidence, character, connection, and competence at the individual, relational, and collective levels in order to make lasting impact.^{40–44} If secondary prevention interventions fail to address the relationships these young women have, and the environment in which they live (i.e., community and society at large), the interventions may fall short of providing lasting and meaningful impact. While behavioral scientists may not be able to change the environment in which young HIV-positive women live, they can empower them with the knowledge, skills, and tools to better cope with daily challenges, develop healthy relationships, and promote self-worth and self-confidence as these critical competencies have the potential to reduce risky behavior.

Limitations

One limitation of this study is the small sample size. Since focus group size was limited at each site in order for each youth to maximally participate in the discussion, increasing the number of groups held at each site might have been useful. However, we recruited women from several geographically

diverse sites, which increases the generalizability of the findings. Another limitation was that the sample was primarily African American. While African Americans make up over two thirds of the HIV cases among youth, greater representation from other racial and ethnic groups, particularly Latinas, could help insure cultural relevance of the developed intervention. Since the purpose of this study was to begin development of a secondary prevention intervention that can be implemented in clinical settings, all participants were recruited from adolescent medicine clinics. Therefore the findings presented here may not represent the same experiences of youth living with HIV who are not engaged with clinical care settings as they are often seen as more at risk than their health seeking counterparts. Similar behavioral interventions will also need to be developed and pilot tested for implementation in nonclinical settings.

Future directions

In order to improve on the cross-sectional limitations of this study, a standing youth advisory committee made up of HIV-positive women was formed to confirm the themes identified from the focus groups and to work with the research team directly in the development of intervention activities. The resulting intervention—EVOLUTION: Young Women Taking Charge and Growing Stronger—is currently being piloted for feasibility, acceptability, and preliminary efficacy through the ATN.

If the intervention demonstrates promise, a full-scale efficacy trial will likely be needed. Similar behavioral interventions will also need to be developed and pilot tested for implementation in nonclinical settings.

While the focus of the study was to better understand the problems, pressures and issues of young HIV positive women, the phenomena of young males insisting on having unprotected sex with their HIV positive female partners after they had been disclosed to was reported across all three sites. While this phenomena has been researched among men who have sex with men, MSM, and a little among African American females, little to no research has been focused on why this may be occurring among men who have sex with women.^{37,39,45–48} It would be useful to know if some of the same factors and perceptions that contribute to unprotected sex among MSM and African American females are contributing to men who have sex with females, such as perceptions of HIV risk, fatalism, optimistic bias, cultural worldviews and power.^{37,45–48} While comprehensive gender responsive HIV prevention programs for young women are needed, exploring the factors and perceptions of young men who have sex with women may help to inform how HIV prevention interventions should promote safe sex for both young men and women in relationships.⁴⁸

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