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"I'm Just like everyone else, I Just Happen to be HIV Positive": Challenges Faced by Young Urban Black Women as they Strive to Achieve Normative Life Goals

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Abstract

Younger, low-income, black women are disproportionately affected by the HIV/AIDS epidemic in the U.S. Using thematic analysis of 20 semi-structured interviews with young women receiving HIV care in an urban east coast setting, this study provides insights on how living with HIV influences these women's future aspirations including economic independence, intimate relationships, and family formation in the context of their socio-cultural and economic environment. One major emergent theme expressed by participants was the desire to be considered normal while seeking to meet the developmental benchmarks of emerging adulthood. Gaining economic independence through education and career opportunities was important, as was feeling accepted and loved by a partner. One prominent example is navigating status disclosure to others, especially potential partners. Most women hoped to establish intimate relationships, and while some had navigated the process of disclosure, the fear of stigma prevented many women from doing so. The ability to safely have and provide for a child was also important to many participants. The results highlight the need for interventions that help younger urban black women living with HIV to develop life skills and a better understanding of their reproductive options so that the additional complexities of living with HIV in an already challenging social and economic environment do not compromise positive disease management throughout adulthood.

Keywords: HIV; Female adolescents; Emerging/young adults; Black/ African American; Urban; Women; Socio-cultural; Childbearing; Disclosure; Condom use

Introduction

Black women aged 25-44 are disproportionally affected by the HIV/AIDS epidemic in the United States, accounting for the majority of new HIV infections among women [1,2]. Compared to women of other races/ethnicities, the rate of new HIV infections among black women in 2010 was 20 times that of white women and nearly 5 times that of Hispanic women (38.1 vs. 1.9 and 8.0 per 100,000, respectively), with most black women (87%) infected through heterosexual sex [1,2].

With the advent of combination antiretroviral therapy, the successful implementation of public health interventions, and improved medical care support strategies, the life expectancy of a person living with HIV has been greatly extended [3,4]. Many now consider HIV a chronic illness characterized by several of the same challenges that accompany other chronic illnesses. Chronically ill individuals must continually negotiate the "emergent" nature of their illness; interpreting and re-interpreting the meaning and significance of their illness, maintaining a positive self-image, managing and reducing negativity, accessing resources, and maintaining their social relationships [4]. This process becomes even more complicated for an illness such as HIV that is highly stigmatizing [3]. Younger HIV positive black women must not only contend with managing their illness, they do so within a context of *intersectional stigma*; that is, marginalization based upon their HIV status, race, gender, socioeconomic status, and sexuality [3,5,6].

Black women are at risk for contracting HIV not only due to high-risk individual behaviors such as drug use, or unprotected sex with multiple partners, but also due to the larger socio-cultural and economic context in which they live [7]. In urban areas of the U.S., high incarceration rates among black men, unemployment, drug abuse, and bisexuality create a sex-ratio imbalance that limits the number of

J Women's Health Care ISSN: 2167-0420 JWHC, an open access journal eligible and acceptable black males [8]. Consequently, female partners are more likely to stay in less desirable relationships often tolerating and even expecting infidelity from their partners, [6,8] thus placing themselves at risk for contracting HIV [7,9]. A study conducted among female, black adolescents in Baltimore found that although young women desired monogamous relationships from both an "ideal relationship" perspective and an HIV/STI prevention perspective, many did not feel confident they could maintain such a relationship given the intense peer pressure their male partners faced to engage in multiple sexual relationships [9-11]. Women's expectations for male partner's financial support and involvement in childrearing have also been diminished due to low rates of marriage and the frequency of male partners having children with multiple women [4,6,9,10]. The natural desire for emotional intimacy and the perceived social status afforded to those in a steady romantic relationship may motivate women to accept their partners infidelities or limited involvement as a father [9,12].

Poverty is also strongly associated with HIV infection. It influences where one lives, decreases health care access, and can destabilize relationships [13]. Lack of health insurance and difficulty navigating

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the health care system are cited barriers to accessing care among black women [7,14-16]. Poor access to care delays diagnosis and treatment of HIV; particularly among poor minority women who often discover their HIV-positive status when they access care due to pregnancy or HIV-related symptoms [7]. Unemployment rates among blacks in the US are at an all-time high. The unemployment rate among black women is twice as high as that among white women [17]. Poverty, lack of quality education, and unemployment coupled with racial and gender discrimination often place black women in a position where viable options for life choices including employment, relationships, and childbearing put them at increased risk for HIV and poor treatment outcomes [4,6].

Prevention efforts are increasingly cognizant of the complex factors that increase HIV risk for young black women. Prevention programs such as *SISTA*, *Sister to Sister*, *Sisters Informing*, *Healing*, *Living*, *and Empowering* (SIHLE) and Focus on Youth are among other socio-culturally relevant interventions designed to empower young black women to reduce STI/HIV risk behaviors by focusing on various issues including; ethnic and gender pride, HIV knowledge, and skills training around sexual risk reduction behaviors and decision making [18,19].

While existing qualitative studies give voice to particular topics (e.g., disclosure, sexual risk, HIV medication, stress and depression) less attention has been given to the everyday experiences of women living with HIV [3,4,20-25]. Researchers such as Watkins-Hayes [3,4] thus call for increased analyses on the ways in which HIV positive black women's social and economic everyday experiences are impacted by the interplay between their health statuses and racial, gender, and class locations [4].

This study focuses on qualitative data that provide insight into how younger black women work to manage their everyday lives while living with a stigmatized disease. In addition to the usual HIV related challenges of behavioral and medical regimen adherence, the interviews addressed participant's efforts to meet universal goals such as establishing economic independence, developing romantic relationships, and having children. These data provide insight into how urban, black women in the U.S. conceptualize their options and weigh competing motivations as they navigate their present and imagine their futures.

Methods

Participant characteristics

Twenty HIV positive women were interviewed in an urban east coast hospital. A majority of patients receiving HIV care in this setting reside in the surrounding urban area and meet income requirements for Ryan White funding. Ninety-five percent of participants were black and the mean age of the participants was 27.9 (SD=8.2, range 18-42 years). The results presented mainly focus on discussions with younger participants ages 18-25 (N=12), however, experiences of older participants are intermittently referenced for comparative purposes. Twenty-five percent of women were perinatally infected. Among the 70% of participants reporting a romantic relationship, 58% were women ages 18-25. Forty-three percent of women were in serodiscordant relationships; while 36% did not know their partner's HIV status (Table 1).

Procedures and analysis

Semi-structured in-depth interviews were conducted with HIV positive adolescent and adult women receiving HIV clinical care in an

urban east coast setting with a high level of HIV infection. Participants were recruited from two clinics affiliated with a large hospital: a designated HIV clinic for adults (N=8) and an intensive primary care clinic that provides HIV-infected youth up to age 24 years (N=12) with specialized care and social support. Interviews took place at the clinic. Oral informed consent was conducted in a private room where the purpose of the study was explained, including the steps that would be taken to ensure their confidentiality. Participants were assured that their responses would in no way affect their care and treatment. A semi-structured interview protocol was constructed to guide the conversation in order to provide consistency and ensure key topics were covered; but it was flexible to encourage detailed and concrete responses from the participants. Topics covered during the interview included living with HIV, future life goals, thoughts on childbearing, intimate partner role and expectations, and coping with HIV. Interviews were conducted in a quiet room in the clinic and lasted an average of 50 minutes. Participants received a \$20 gift card to a grocery or retail store in appreciation of their time. Interviews were digitally recorded and transcribed verbatim.

Transcripts were thematically analyzed and independently coded by two study team members. The process involved a grounded theory approach where themes, categories, and patterns were identified through careful reading and re-reading of the data [26]. These categories were refined through an iterative process of individual coding. A larger study team further reviewed and refined themes.

Results

The results presented are organized around major themes that emerged through the analysis process and common trends across participants. For each theme, participant quotes aim to reveal how underlying tensions resulting from their HIV status, and in some cases their socio-economic environment, constrain goals or opportunities to more safely navigate live with HIV.

Living with HIV as a chronic illness

When asked how having HIV/AIDS affected their daily lives, participants conveyed the need for a sense of normality in their lives. One participant passionately stated, "I'm just like everybody else, I just happen to be HIV positive" (ID 1, age 29). Another participant minimized the distinction of HIV from other chronic illnesses explaining that HIV is "just like a chronic illness that you have to maintain" (ID 18, age 23). Other participants initially tried to downplay the effect of HIV in their lives. Further discussion, however, revealed a greater impact than initially reported: "It [HIV] doesn't affect my life too much... It affects it a little bit because by me having to worry about the outcomes and the medication" (ID 13 age 18). Although participants wanted to be considered normal and pursue normative

Characteristic	Total Sample (N=20)
Age: mean (SD)	27.9 (SD=8.57)
Age: range	18-42
Race: N (%) Black White	N=19 (95%) N=1 (5%)
Perinatally infected: N (%)	N= 5 (25%)
Currently with a romantic partner: N (%)	N=14 (70%)
Partner Serodiscordant	N=6 (43%)
Partner Status unknown: N (%)	N=5 (36%)
Condom Use: N (%)	N=9 (64%)

Table 1: Participant Characteristics (N=20 women).

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goals, as the following sections show, their HIV status and expectation from men, influenced important aspects of their lives.

Independence: desire for educational attainment and economic stability

When asked about their future aspirations, the most important goal the women articulated was a desire to be economically independent through education and stable employment. Educational and financial goals ranged from completing high school or a college degree, becoming a pediatric nurse, owning an apartment or house and buying a car. Some women expressed concrete and detailed immediate goals. For example, two participants succinctly articulate their goals of independence and security:

Right now I'm going for a hospital diploma thing on the computer. Hopefully I'll be finished there... already in college or starting college. And...have a decent enough job [so] I'm okay, I can afford to pay all my bills and live comfortably (ID 7, age 24).

If I had a crystal ball I would like to say I want to be able to buy my house. I want to have my own place...I want to...get over the fear of driving and just be secure at the age of 21. (ID 15, age 19).

Although education and employment are salient goals for these women, obstacles as a result of one's HIV positive status and lack of practical guidance were still considered. For example, a 23 year old woman shared her concern that her HIV positive status might hinder her from achieving her goals: "I want to do nursing, but then I be scared because of my sickness, like working around blood and patients...". It was also evident that although some participants wanted to complete their education, they felt doubtful or unsure they could achieve the goal.

I plan to finish some type of schooling program. Don't really know what, don't know really how, but that's what I have planned to do and if I don't do it now, then it's probably never going to get done (ID 4, age 21).

Intimacy: desire to form romantic relationships

Entering, negotiating, and maintaining romantic and sexual relationships is challenging even under optimal circumstances. When one is HIV positive, the process of establishing relationships is even more complicated. Thirteen of the 20 participants expressed the desire to have a romantic relationship and many participants hoped to marry someday. Participants shared that they wanted to "find the right person" (ID 2, age 20) or somebody who they can "be comfortable with" and "be with for a while" (ID 6, age 18). As one participant put it: "I plan to have a relationship... I always, you know, dream to be married one day. But you just got to find the right one...cause that is a dream to get married one day" (ID 17, age 20).

Disclosure is an important part of forming romantic relationships as it helps create trust and intimacy [27,28]. This process is difficult for younger women living with HIV as they not only grapple with the normal challenges of forming intimate relationships, they have the additional concern of deciding whether to disclose their status and face the potential rejection that may ensue due to the stigma attached to HIV. Although participants expressed a desire to form romantic relationships, a tension [29] existed between their need to be open and disclose their status and their need to maintain privacy and protect themselves against negative social outcomes such as stigmatization, rejection, and isolation. For instance, one participant admitted that even though she dated for a year, she never disclosed her HIV status "I mean he still doesn't know because it didn't get to that serious point, you know, when he was like oh well can we do it without? (a condom)...I wasn't really comfortable explaining it, you know so that's why the relationship didn't go anywhere" (ID 17, age 20).

For some participants, the fear of disclosure prevented them from pursuing intimate or sexual relationships altogether. A 23-year-old participant explained that although she wants to date, she stays single due to her fear of disclosing her status:

"I want to date...but at the same time I'm scared cause I have to tell them my status and I'm not up for that...I don't know what to do...I wish I could find somebody that was in the same predicament that I was in...I guess I'll be single for a long time" (ID 12, age 23).

Interviews with older participants showed that disclosure does not necessarily become easier with age thus learning to do so early may be an important skill:

"It's hard for me to say I have HIV... So I know I'm not going to tell my partner, even though I don't have one right now, but I'm just saying I can't tell them because they going to look at me totally different and they might leave" (ID 20, age 25).

Motherhood: desire to have children

Of the 12 participants ages 18-25, eight participants expressed the normative desire to have children. As one participant put it:

"When I see people with kids it ... influences me. I want to be a mom...my boss just had a baby and just being around her and seeing... it just makes me like I want this, I want to be a mom, I want to be one right now" (ID 15, age 19).

Their desire reflected not only their own wishes, but also the sociocultural expectations of their family, friends, and partners who often encouraged them to have children. Sometimes this encouragement was perceived more as pressure (even if manageable): "I was talking to my mother about that when she was living and she was like... 'I'll be glad when you have some kids.' I said 'mom you gotta be patient'" (ID 17, age 20).

The desire to have children led several participants to engage in the dangerous practice of inconsistent condom use. As one participant shared:

"We use condoms, but I think sometimes he be taking them things off. He don't pressure me but I really do think he want one (a child). The reason why I think... he take them off because he has talked about having children" (ID 7, age 24).

The presence of an interpersonal power imbalance was evident when a participant indicated that her partner controlled the times they did not use condoms because of his desire to have children with her:

"We have been having unprotected sex for seven years, (laughing)... but um, we...do use condoms sometimes and then I guess when he's in the mood that he wants to have a baby or he wants to try and get me pregnant we won't use a condom" (ID 3, age 22).

Economic considerations also played an important role when discussing childbearing desires. Participants' hopes to have children were often predicated upon their ability to be financially stable. One participant described the ideal situation: "Um...I...tell everyone I would like to have kids in the next five years. I started saying that like two years ago so (laughs)...I don't want to bring a child into the world and we don't have a stable roof and we don't have money in the bank so once I get those two things rolling, then my future as far as children and family comes next" (ID 3, age 22).

As much as participants hoped to have children, it was not lost upon them that their HIV status might make this difficult. For example, a 25-year-old participant declared she would not have children because of "the situation". Another participant reported a change in her childbearing desires because of her HIV diagnosis.

"I used to say I want a child, but since I found out I'm sick I'm not too thrilled about having any children. I would love to have some, but I don't see that as an option for me not any time soon...I don't want to pass this along to my child" (ID 7, age 24).

In addition, although most participants hoped to have children within an "ideal relationship" (long term and monogamous), many expressed the probability that they would shoulder the responsibilities of childrearing alone because support from male partners is uncertain:

"I don't think he'd probably even support me. Not that I would need anybody to support me, but I don't think he would stick around. I don't know, I don't even want to take that chance" (ID 4, age 21).

In some cases, this lowered expectation was a reflection of participant's own childhood experiences:

"You gotta know what you're going to do with or without them...I learned that from my father. He either going to take care of you or not take care of you..." (ID 15, age 19).

"Cause you know you'll have a baby by them and then they'll leave...and plus after you get pregnant they basically sometimes don't want nothing to do with you...I guess I would like a father... that's there...because my father wasn't basically there that much" (ID 2, age 20).

Discussion

Women's own life experiences and examples of their peers' lives shape expectations for their own options and expectations of themselves and intimate partners. For many, an HIV diagnosis will limit life goals and expectations if additional support and training is not provided. Human beings are often motivated by future aspirations to engage in positive behaviors [30]. For younger women living with HIV, having future goals may be even more important as it can encourage behaviors that will help extend and improve their quality of life (e.g., medical and behavioral adherence). Participants expressed goals that were typical of their developmental stage such as establishing economic independence and romantic relationships. This is consistent with results from a qualitative study examining gender ideologies among black adolescents [10] where establishing economic independence and having a male partner was equated with "being a woman". Achieving these goals may, however, be difficult for these participants as they live within a larger social context that has limited educational and professional opportunity structures available to them due to racial, gender-related, and economic barriers, [9-11] and stable male partnerships are less common. Participants who desired children hoped to be in a stable relationship before they had children, however, several voiced their uncertainty that their partners' could fulfill the role of father and partner. While partner support was desired, many felt they could be strong enough to raise a child on their own. Without a clear understanding of the risk of perinatal transmission or strategies to reduce risk to partners, as described in previously published data from this sample [31], participants miss opportunities to protect themselves, their partners and future child.

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Implications for practice

While many of the social and economic conditions that serve to further complicate the decisions and expectations of black women living with HIV are structural in nature and thus more effectively modified by policy level changes, there are efforts at the community and individual level that can support improved options for these women. Skill-based training can increase employment opportunities for young HIV positive black women regardless of their graduation status. Identifying and linking patients with culturally appropriate skillsbased community programs can provide a variety of services including: educational and vocational planning, professional skill building, access to internships, employment, or even micro-finance opportunities. HIV providers could develop networks that link younger black women to HIV positive mentors from similar backgrounds who have overcome health and socio-cultural/economic barriers to become successful in their endeavors. Programs such as Together Learning Choices, Choosing Life: Empowerment! Action! Results! (CLEAR), are great examples of interventions that focus on providing HIV positive youth with skills to live healthy, positive, lives. However these programs are targeted towards HIV positive youth in general. This study suggests that there may be value to providing tailored interventions that address the particular needs of young black women.

Furthermore, healthcare providers caring for younger women living with HIV need to openly discuss their childbearing desires and engage them and their partners in preconception planning to reduce risk of partner or infant transmission when they are ready for that step. Providers should thus take the opportunity to develop or adapt existing protocols to refer patients to appropriate services for reproductive health counseling to ensure that young women know that they have the option to achieve parenthood safely.

Strengths and limitations

This study acknowledges the social determinants of health and that health decision making reflects these realities in women's responses to important aspects of their lives that have significant implications for their own health and that of others. It also includes the voices of younger women (18-25 years), including those who have lived with HIV since birth, to include participants who are less likely to be included in research studies. The smaller qualitative sample limits the generalizability of these findings. Including the perspectives of the participants' partners would have provided a richer and more accurate understanding of the influences of socio-cultural and economic factors on their options and motivations.

Conclusion

Participants expressed normal life goals of economic independence, intimacy, and childbearing that have become further complicated by their HIV-positive status and their social and economic environment. Intervening early with younger women living with HIV presents a critical opportunity as the development of life skills for living with HIV can shape positive behaviors and outcomes for the rest of their adult lives.

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