

# Project DASH: (Divas Against the Spread of HIV/AIDS): Results of a Pilot Study on HIV Risk and Mother-Daughter Communication Among HIV+ Mothers with African American Daughters

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## Research article

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# Abstract

**Background:** Daughters of HIV positive women are often exposed to similar factors that placed their mothers at risk of HIV. Compared to women of other racial/ethnic groups, African American women have disproportionately higher rates of HIV/AIDS. This pilot study examines the relationship between African American HIV positive mothers and their daughters, and this relationship's association with mother-daughter HIV risk communication and related domains.

**Methods:** This mixed-method study employed quantitative surveys and qualitative interviews. All participants completed the quantitative survey while qualitative data were collected from a subset of participants.

**Results:** Ninety-eight percent of respondents were African American, 73% had been HIV-infected for at least 10 years, and the mean age was 49.9 years. Among daughters, 85% reported feeling comfortable talking to their mothers about sex.

**Discussion:** Results underscore the need to strengthen the mother-daughter communication around these topics in ways that may positively influence the sexual behaviors of the daughter.

## Background

Despite significant advances in Human Immunodeficiency Virus (HIV) prevention and treatment, disparities still persist in the U.S. HIV epidemic. African Americans represent approximately 12% of the U.S population, yet accounted for 45% of new HIV diagnoses in 2018, as well as the highest prevalence of those living with HIV (1). African Americans living with HIV also experience the lowest rates of viral suppression among all racial/ethnic groups, and the second to lowest rates of receipt of and retention in care (2). Compared to women of other racial groups, African American women continue to face the most severe burden of HIV and acquired immunodeficiency syndrome (AIDS) (3). In 2018, the HIV diagnosis rate for African American women was 13 times higher than that of white women, and almost four times that of Hispanic women (1). A diagnosis of HIV is associated with a number of stressors including perceived and actual stigma, depression, medication adherence, and social and familial isolation, all of which are experienced by African American women (4). These stressors further exacerbate the physical and emotional well-being of low-income minority HIV-positive (HIV+) women.

Studies reveal that in adolescents between the ages of 10–19, more than two million are living with HIV, with millions at risk for infection (5). Currently, adolescents of parents living with HIV are understood to represent one of the highest risk groups for their own HIV infection (6). There is a crucial link between the communication of a mother to her daughter when it comes to HIV risk behavior (7). Mothers mainly, play an influential role in the communication of risky sexual behaviors and actions done by adolescents (7). Daughters of HIV positive mothers often are faced with the same social, structural and environmental exposures that heighten risk and vulnerability to HIV (8). HIV positive families are often faced with conditions such as illegal substance use, racism, poor education systems, and urban violence (8). These

conditions make the youth of these HIV positive families more likely to engage in risky behavior at a young age (8). Because of this, it is necessary that HIV + families communicate with their children in order to discuss certain activities that put them at risk.

One approach to reducing HIV incidence is by engaging parents, particularly mothers, in the sexual socialization of young women. The utility of mother-daughter communication in mitigating sexual risk in daughters has been established (6, 9, 10). Communication about sexual risk has been identified as one of the most effective parenting behaviors that mitigate sexual risk in children, especially daughters (11). Daughters are more likely to communicate with their mothers, especially around issues about sex and sexual behavior, than they are with their fathers (12, 13). High levels of parent-child communication and connectedness between parents and children has been positively associated with consistent condom use, abstinence, delayed sexual initiation, condom self-efficacy, sexual communication with their partners, and high self-esteem (11, 13–15). Given the burden of HIV among African American women, communication between HIV + mothers and their daughters may play a role in mitigating HIV risk. As such, in this pilot study, we explored the relationship between sexual communication of HIV + women and their daughters and the HIV risk and sexual behaviors of the daughters.

## Conceptual Framework

The conceptual model (see Fig. 1) is a visual representation of the central constructs guiding the aims of the study. Specifically, the context of the mother-daughter relationship and its impact on communication will serve as the focus of the study. This study builds on Geri Donenberg's social personal framework on HIV risk behavior. The framework currently highlights the relationships between personal attributes, family context, peer and partner relationship concerns and environmental circumstances (16). We focus on the role of mother's attitudes and behavior on sex and its interaction with parent-child communications among HIV + women. The mother-daughter relationship is mediated by many pathways, such as the mother's route of transmission, and the quality and context of the way mothers and daughters communicate. This framework allows us to consider how these mediators effect the relationships between the broader dimensions of personal attributes, peer and partner relationship and environmental circumstances.

The evidence for the role of parent-child communications in mitigating risky sexual behavior is clear. However, the content of these communications and the degree to which they are informed by the mother's own HIV + experiences are not. Parent child communication among HIV + mothers is a unique relationship mediated by the mother's on route of transmission and the quality and context of the mother daughter relationship. Some studies have found communication among this group is focused on HIV status disclosure and safe sex practices, neglecting conversations on sexuality, sexual engagement, and negotiation of practices with male partners. This study aims to evidence determinants of more effective mother-daughter communication practices with the goal of positively influencing the sexual behaviors of the daughter.

## Methods

A sequential approach to collecting both quantitative and qualitative was used to obtain data from study participants. Quantitative data was obtained using anonymous pencil and paper surveys while qualitative data were obtained through individual interviews.

Face-to-face qualitative interviews were conducted using semi-structured interview guides with open-ended questions and probes.

Interviews were held in private areas, audio-recorded and lasted approximately one hour. All audio-recordings were subsequently transcribed verbatim and analyzed for emergent themes.

Signed written informed consent forms were obtained from all participants prior to quantitative and qualitative data collection.

Anonymity and confidentiality of the participants were assured, as there was no identifying information reported in the aggregate. Participants received compensation of \$20 for the quantitative phase and \$30 for the qualitative phase of the study.

Institutional Review Board (IRB) approval was received from Montclair State University and Yale University.

## Participants

Eligibility criteria for mothers included being 18 years and older, self-identify as African American, being a mother of a female child, and self-reported as HIV+. Eligibility criteria for daughters included being 18 years and older, having a mother who was HIV + and self-identify as African American. Participants were recruited from the waiting rooms of HIV/AIDS clinics and community-based organizations that serve HIV-infected, and other vulnerable populations in the greater Newark, NJ area of Essex County between June and September 2014. As of 2016, Essex County has the highest rate of HIV prevalence out of New Jersey's 23 counties. A total of 74 participants (51 HIV-infected mothers and 23 HIV-uninfected daughters) took part in the quantitative surveys while 30 unpaired participants (15 HIV-infected mothers and 15 HIV-uninfected daughters) took part in the qualitative interview.

## Interview Guide & Quantitative Survey

Three trained research assistants conducted face-to-face interviews using a semi-structured interview guide that was framed in prior qualitative studies on mothers and daughters. Additionally, separate interview guides were developed for the mothers and daughters ( Supplementary files 1&2). The interview guide included open-ended questions and probes. The interview guide was cognitively tested and pilot-tested on a sample that fit the inclusion criteria for the mothers and daughters and was subsequently revised accordingly. Mothers were asked to describe how they talk to their daughters about HIV risk and the difficulty in initiating these conversations. The study utilized a concurrent triangulation design.

Daughters were asked whether they talked to their mothers about HIV risk and risk-reduction strategies,

and to describe how they had these conversations with their mothers. Examples of questions that daughters were asked include “Do you feel you are at risk for HIV?” Quantitative data collected included information on sociodemographic characteristics (race, marital status, annual income, education), sexual behavior (age of sexual debut, number of sexual partners in past three months, history of sex under the influence of drugs/alcohol, exchange sex, condom or dental dam use at last sex, ever had STI, and time since HIV diagnosis), and healthcare utilization.

## **Data Analysis**

Statistical Program for Social Sciences (SPSS) version 20.0 was used to analyze the quantitative data. Frequencies and descriptive statistics were conducted to characterize the sample. The qualitative data was coded using ATLAS.ti 7 software. Codes were generated based on the research questions, as well as inductively, through open coding and data immersion. A second rater coded all the transcripts and consistency was achieved between both coders.

## **Results**

### **Quantitative Results**

#### **Mothers**

Table 1 shows the socio-demographic, sexual behavior, and practices of the HIV + mothers in the study sample. Ninety-eight percent of mothers in the study were African American. Mothers’ age ranged from 35 years to 66 years old (mean age 49.9 years). Of participants who reported their highest level of education, 31.3% reported high school or less (no diploma/no GED), 39.2% reported a high school diploma or GED, 27.4% reported having greater than a high school diploma or GED.

Table 1  
Socio-demographic, sexual, and healthcare utilization characteristics of mothers (N = 51)

Variable	N (%)*
Demographics	
<b>Race</b>	
Black	50 (98%)
Hispanic/Latina	1 (2%)
<b>Age (Range)</b>	35–66
Mean (SD)	49.9 (8.1)
<b>Highest level of education</b>	
High school or less (no GED)	16 (31.3)
High school graduate/GED	20 (39.2)
Some college/technical/vocational	13 (25.4)
College graduate or professional degree	2 (3.9)
<b>Marital status</b>	
Married	6 (12%)
Long-term relationship	11 (22%)
Other (single, divorced, separated, widowed)	33 (66%)
<b>Annual income</b>	
0-\$24,999	14 (28.6)
\$25,000-\$34,999	30 (61.2)
\$35,000-\$44,999	3 (6.1)
≥\$45,000	2 (4)

\*responses may not sum to N because of missing data

#Among participants who required medical care

<b>Variable</b>	<b>N (%)*</b>
Sexual behavior	
<b>Age at first sexual intercourse (oral, vaginal, or anal)</b>	
11 years or younger	7 (13)
12 years	5 (9.3)
13 years	11 (20.4)
14 years	4 (7.3)
15 years	8 (14.8)
16 years	7 (13)
≥ 17 years	12 (22.2)
<b>Number of sexual partners in past three months</b>	
1	26 (47.3)
2	2 (3.6)
Had sex but not during the past three months	16 (34)
Don't know or can't remember	3 (5.5)
<b>Ever had sex under the influence of drugs or alcohol</b>	
Yes	35 (74.5)
No	12 (25.5)
<b>Used alcohol or drugs before sex at last sexual encounter</b>	
Yes	11 (22.9)
No	37 (77.1)
<b>Used a condom or dental dam at last sex</b>	
Yes	36 (76.6)
*responses may not sum to N because of missing data	
#Among participants who required medical care	

<b>Variable</b>	<b>N (%)*</b>
No	11 (23.4)
<b>Ever exchanged money or gifts for sex</b>	
Yes	21 (41.2)
No	30 (58.8)
<b>Ever had an STI</b>	
Yes	41 (77.4)
No	12 (22.6)
<b>Time since HIV diagnosis</b>	
0–6 months	1 (2)
4–6 years	3 (6.1)
7–9 years	9 (18.4)
≥ 10 years	36 (73.5)
<b>Healthcare utilization</b>	
<b>Ever put off medical care in past 12 months because of lack of health insurance or affordability<sup>#</sup></b>	
Yes	9 (18.4)
No	40 (71.6)
<b>Comorbid medical conditions</b>	
Yes	32 (60.4)
No	21 (39.6)
<b>Number of medical comorbidities</b>	
1	47%
*responses may not sum to N because of missing data	
<sup>#</sup> Among participants who required medical care	

Variable	N (%)*
≥ 1	53%
*responses may not sum to N because of missing data	
#Among participants who required medical care	

Table 2  
Selected Socio-demographic characteristics of the sample of  
daughters (N = 23)\*

<b>Variable</b>	<b>n(%)*</b>
<b>Race</b>	
Black	20 (100)
<b>Age, years (range)</b>	
Mean (SD)	16–42 29.2 (7.8)
<b>Highest level of education</b>	
High school or less (no GED or diploma)	7 (35)
High school graduate/GED	11 (55)
Some college/technical/vocational	1 (5)
College graduate or professional degree	1 (5)
<b>Marital status</b>	
Married	2 (9.5)
Single	8 (38.1)
In a relationship (dating)	9 (42.9)
Other (divorced, separated, widowed)	2 (9.5)
<b>Annual income</b>	
0-\$24,999	12 (60)
\$25,000-\$34,999	4 (20)
\$35,000-\$44,999	2 (10)
≥\$45,000	2 (10)
<b>Employment status</b>	
Unemployed	9 (47.4)
Employed (full-time)	7 (36.8)
Employed (part-time)	2 (10.5)
Other (social security, disability)	1 (5.3)
<b>Sexual Behavior</b>	
<b>Ever had sex under the influence of drugs or alcohol</b>	

Variable	n(%)*
Yes	14 (70.0)
No	6(30.0)
<b>Used a Condom or Dental Dam at last sex</b>	
Yes	(67.0)
No	(33.0)

Sixty-six percent of participants were single; the majority (89.8%) reported an annual income less than \$35,000. Regarding their sexual behavior, 77.8% were 16 years old or younger at first sexual intercourse, 74.5% reported ever using alcohol or drugs before sex, 57.4% reported at least one sexual partner in the previous three months, 22.9% reported using alcohol or drugs before their last sexual encounter, and 76.6% used a condom or dental dam at last sexual experience.

Approximately 41.2% of participants had ever exchanged money or gifts for sex and 77.4% reported a history of STI.

Most participants (73.5%) had been living with HIV for 10 or more years. Among participants who required medical care, 18.4% did not seek medical care because they lacked health insurance or could not afford it. About 60% of respondents reported an existing co-morbidity while 53% had more than one comorbid condition (i.e hypertension, diabetes, depression and cancer).

### **Daughters.**

The daughters (N = 23) ranged from 16 to 42 years of age with a mean age of 29.2. Most of the daughters (55%) reported graduating from high school or holding a GED; 38.1% were single. In terms of employment, 47.4% reported they were unemployed and 47.3% reported working part time. Thirty five percent of daughters indicated having their first sexual intercourse at the age of 17. Nearly three-fourths (74.5%) reported ever having had sex under the influence of drugs or alcohol. Results also showed that 26.3% of daughter reported contracting an STI at least once. Seventy percent of daughters stated they have had sex under the influence of drugs or alcohol. One-third of daughters reported not using a condom or dental dam. Nearly one-fourth (23%) reported not using condoms or dental dams at last sexual intercourse.

### **Mother-daughter communication.**

Table 3 shows that 82% of mothers reported being quite close or extremely close with their daughters. About 85.7% of mothers were satisfied with the level of communication with their daughters. 90% of daughters described the relationship with their mothers as quite close or extremely close and 85% were comfortable discussing sexual topics with their mothers.

Table 3  
Quantitative Results for Mothers (n = 50) and Daughters (n = 20)

Variable	n (%)
<b>Close relationship with daughter**</b>	
Not close at all	2 (4)
Somewhat close	7 (14)
Quite close	29 (58)
Extremely close	12 (24)
<b>Satisfied with mother-daughter communication**</b>	
Strongly agree	31 (63.3)
Agree	11 (22.4)
Neither agree or disagree	4 (8.2)
Disagree	2 (4.1)
Strongly disagree	1 (2)
<b>Close relationship with mother###</b>	
Not close at all	<b>0 (0)</b>
Somewhat close	<b>2 (10)</b>
Quite close	<b>5 (25)</b>
Extremely close	<b>13 (65)</b>
<b>Comfortable discussing sexual topics with mother###</b>	
Strongly agree	13 (65)
Agree	4 (20)
Neither agree or disagree	2 (10)
Disagree	0
Strongly disagree	1 (5)
** respondents are mothers	
### respondents are daughters	

## Qualitative Results

Thirty women (15 mothers and 15 daughters) participated in the qualitative interview phase. Analysis of the qualitative interviews revealed 5 themes: 1) communication characteristics between mothers and daughters and the underlying process in this relationship, 2) experiences with HIV and health, 3) barriers to healthcare access for the HIV + mothers, 4) social support, and 5) lack of social services.

### **Communication between mothers and daughters.**

Mothers and daughters both reported that they have a good relationship however; they both expressed a lack of communication about the specific topic of HIV. When describing communication characteristics between mothers and daughters and the underlying process in this relationship, one mother reported, "I know she probably tell me the truth about whatever she is telling me, but not everything." Daughters expressed similar sentiments, with one stating, "well, when she first brought it to my attention, that was like...uh...you know, our first conversation. And it kind of took me by surprise...we don't talk about it ever. That was only like...It was, like, the first time. I mean, it's been mentioned, but to, like, sit down and actually have a conversation? No."

### **Experiences with HIV and health.**

Participants reported having average to good health; however comorbidities played a significant role in participants reporting average health. The majority of participants reported having hypertension, cancer, a physical disability and mental illness such as depression. When discussing illness, one mother said, "um...I have neuropathy, so I have a problem walking now. That's been about two years, now. Um...I battle cervical cancer. I went through therapy for like, five months of...going through the radiation. And my memory is not as well as it used to be, because I have seizures also. So, just battling that is a lot. My main thing...I think I can deal with everything but the walking; 'cause it's... now, I'm on a walker." In determining opportunities for self-care, mothers reported "Um...Just more consistent on my medication" and "don't miss no doctor appointments...um...stay on top of my meds...um...just take...just taking care of yourself. That's the bottom line."

Daughters also described issues, with one stating, "um...Because I am...I...I'm not 100%. Like, I'm anemic. Um...I have a...a physical disability. So, that's why it's not 100. It's just good."

### **Healthcare access.**

With regard to health care access, many participants reported not having health facilities in their neighborhoods or those close enough that offer health services they needed. Participants described a variety of barriers to healthcare access. The major types of barriers to access reported include transportation, procrastination, family issues and the physical environment. Strikingly, one mother stated, "I get...I'm tired of catching buses. Some buses can be very stressful, because...One day I caught eight buses to handle my business...to make it happen," exemplifying the extreme extent to which some must go to receive care.

### **Social Support.**

Regarding the issue of social support, the majority of participants reported family, friends, significant other and support groups as their main source of support. Daughters were more likely to identify friends and siblings as a source of support, such as one daughter who stated, "Um...As far as support, I mean, I can...I can go to my mom, but I feel like I can go more to my sister." In contrast, mothers were more likely to identify family and significant others as source of support, as indicated by one mother directly: "friends, family, my husband, you know...which is also positive... And so, I have him to fall back on." One mother identified family relationships as a motivating factor for the future, saying "um...I wanna be around for my grandkids when they become teenagers. ..They motivate me. Even though they don't live with me, but my grandson stays there all the time. So, I wanna be around for them. They're motivation... and my son."

### **Lack of social services.**

According to many participants, there is a lack of social services in their neighborhoods specifically for HIV + individuals. In addition, many participants reported they have to commute to different neighborhoods to receive the necessary services that are lacking in their community. When asked if there were any local resources available, one mother responded, "not in this neighborhood," and a daughter concurred that "the church has services but that's not.. in our neighborhood."

## **Discussion**

### **Mothers**

Mothers living with HIV in this study live with other diseases such as diabetes, hypertension, depression and cancer. Mothers faced struggles related to access to healthcare, including lack of transportation to and from health care facilities. One mother described that she had to take eight buses to get to a healthcare facility in order to receive care. Behavioral issues such as alcohol consumption, drug abuse, non-adherence to treatment and unsafe sex practices were some of the challenges the mothers in this study had to contend with.

These mothers faced these challenges and also maintained the responsibility of raising their daughter. The responsibility of raising a daughter requires a mother to be there for her daughter physically and emotionally, as well as having conversations about sexuality and sex. According to the quantitative findings in this study 58% of the mothers said they were quite close to their daughters, which is consistent with previous research in which mothers with HIV maintained a positive maternal identity and relationships with their children (17).

The daughters in this study reported they had a good relationship with their mother. Sixty five percent of daughters reported being extremely close with their mothers. The mothers and the daughters' survey results affirm that despite the mother's HIV status and the challenges that come with it, the mother and daughter maintain a close relationship. It is this close relationship where an opportunity to develop new strategies around HIV prevention and communication among African American women can be initiated.

In this new strategy, mothers can use their life experiences in educating their daughters about living with HIV and the importance of preventing it. Communication is crucial in order for mothers to use their own narratives of living with HIV to educate their daughters and serve as a resource to their daughters as they make sexual decisions. The findings from the study indicate that 65% of the daughters reported that they could go to their mothers when they have questions about sex. Even if the daughter is aware of her mother's life story with HIV, it does not imply that they have the necessary skills or self-efficacy to make the best decisions about sex. This is supported by these findings as the daughters indicated that even though they are aware of their mother's HIV + status, they often do not talk about it with them. This may represent a missed opportunity for mothers to share and daughters to learn from their lived experiences with HIV, which could further contribute to daughters' knowledge and inform decision-making (18).

In relationships that were reported as close by both the mother and daughter, disclosure was more likely to be open and direct, which signified that the mother had informed her daughter of her HIV status, as opposed to just informing the daughter of a "sickness." In these cases, the mother was also more likely to have shared with the daughter more information about her mode of transmission, and consequently, use this testimonial as a means of prevention and awareness for her daughter. It is important to note here again, often even in such relationships within the current study, it was found that communication did not regularly or frequently arise related to HIV and STIs. For example, the daughter may be fully aware and supportive, assisting her mother with medication regimen adherence or regularly checking on mother's condition, however, reported no frequency or regularity in discussions on or communication on topics related to HIV prevention or STIs. Conversely, relationships that were not reported to be "open" or "close" often experienced disclosure in a more indirect way, as opposed to direct. In indirect disclosure, as used in this study, the mother may have communicated to her daughter that she often does not feel well or has to take medication regularly, however, has not disclosed her positive HIV status, denoting indirect disclosure. These relationships often, therefore, did not advance to communication about mother's mode of transmission, and furthermore, did not rely on the maternal experience as a means of testimonial prevention. Daughters in this case were often present but on the outskirts of her mother's illness.

Awareness of a mother's HIV status does not automatically imply that daughters are knowledgeable about HIV/AIDS. Thus, even daughters whose mothers are living with HIV can be at risk of contracting HIV even though they know their mothers' status. According to previous work by Murphy et al. (19), despite their HIV status, some mothers refrained from discussing sex and HIV risk with their daughters because they were either too embarrassed or they did not perceive it necessary (19). This suggests that mothers can share the journey of living with HIV with their daughters but they need to facilitate communication about safe sex and the importance of preventing the spread of HIV. Using their life stories in relation to educating their daughters about safe sex can contextualize the challenges of living with HIV/AIDS. This strategy allows mothers who live with HIV to not only encourage their daughters to practice safe sex, but encourage them to do so whilst reflecting on their lived experiences and their unique challenges of living with the virus.

Mothers interviewed in the present study were asked about their overall health behaviors and self-care particularly regarding HIV/AIDS. In questions regarding self-care, better nutrition, increases in daily exercise, and stress reduction were the overall areas in which participants expressed a need for change. Almost all women said that they needed to eat better, be more physically active, and reduce stress regarding personal relationships. In general, mothers in the study said that they were close with their daughters and that they had open dialogue about sex and STI/pregnancy prevention. All mothers cited their children (and grandchildren) as their main motivators in taking care of their health.

## Daughters

Daughters who were interviewed reported that they had an open dialogue with their mothers about sex. The dialogues described by the daughters were cautionary in nature; the messages that they received from their mothers encouraged safe sex in order to prevent unwanted pregnancy and STI. The daughters talked about their experience of their mothers' disclosure to them. As in the case of the mothers who were interviewed, this narrative was paramount in understanding attitudes, knowledge and beliefs regarding HIV/AIDS. Fear of stigma towards their mothers was an issue that emerged in this study. Besides being caretakers, daughters reported that they became "protectors" of their mothers as well.

## The Mother-daughter Dynamic

This study was able to capture accounts from both mothers and daughters. This was valuable in being able to observe the direction connection between mothers and daughter surrounding issues of sex, HIV/AIDS, and the quality of intergenerational communication.

Most participants viewed their relationships as "close" and expressed love for the other. A salient theme that arose amongst and across mothers and daughters was an emphasis on caring for others, sometimes at the expense of self-care. "Putting others first" was the most mentioned principle in both mothers and daughters. Ironically, participants in both groups cited this mantra as a major source of stress. Being able "to do" for others emerged as a sense of pride in both groups, and in both groups women expressed a sense of "burnout" in some of their personal relationships.

A major opportunity for intervention emerges at the juncture of disclosure from the mother to the daughter. This fact was elucidated in an interview of two sisters (daughters) of an HIV + mother in this sample. At the point of interview, the mother said that she went directly into treatment and was offered services that addressed her physical wellbeing, as well as her mental and emotional wellbeing immediately. However, interviews with both daughters revealed that they themselves have gone 15 years from the time that their mother disclosing her status to get tested. Both daughters mentioned that they never processed their own emotions properly because they went directly into caring for their mother. This is just an example of a common theme among a number of participants. Both mothers and daughters expressed "putting others first" as a highly prioritized mode of living for themselves which could be an

effective manner of systems prevention. Mother-daughter dyads may be a prime target for effective interventions to increase sexual risk communication (20).

The mother/daughter relationship, as well as life experiences of the mother, has the potential to form a highly effective foundation for open communication about safer sex and prevention of HIV. Other social relationships where HIV + individuals can use their life experiences as a basis of starting conversations may also be an effective foundation for establishing open communication about safer sex and prevention of HIV.

The research of this study shows the need for support groups in which daughters of HIV + mothers are encouraged to their mothers but also take appropriate care for themselves.

These groups have the potential to offer an extended social support branch and encourage positive health behaviors that were found to have been neglected in favor of other responsibilities related to their mothers' HIV status and their sense of "protector" in the relationship.

## **Limitations**

The study is not without limitations. The small sample size for both the mothers and daughters and the use of a convenience sample prevent the results from being generalized to all African American HIV + mothers and HIV negative daughters. Secondly, the participants in this study were all recruited from community based organizations and foundation that serve women affected with HIV/AIDS and other vulnerable population in the Newark metro area New Jersey. This limits the diversity of the group and should be interpreted within those parameters.

## **Implications**

Mother-daughter relationships and life stories of the mother should form a basis of open communication about safe sex and the importance of preventing HIV. This strategy can be expanded beyond the mother-daughter relationship to other social relationships where HIV + individuals can use their life experiences as a basis of starting conversations and promoting prevention. A major opportunity for intervention emerges at the juncture of disclosure from the mother to the daughter. Both mothers and daughters expressed "putting others first" as a highly prioritized mode of living for themselves which could be an effective manner of systems prevention.

In addition to existing support groups, there should be continued and expanded social services for women living with HIV in urban, low income areas. Expanding social services that are easily accessible to residents would increase the likelihood of fidelity participation in social services and medication adherence. Mental health counseling regarding methods to effectively disclose as a form of prevention for HIV/AIDS and other STDs should also be available to this population. This method of prevention can prove to be a tangible, culturally sensitive technique that can positively impact the experiences of urban life and families. Public health educators have the responsibility to educate this vulnerable population to

effectively execute this technique for HIV prevention by equipping them with knowledge and training around use of their life stories as related to health information about HIV for the greater community.

## **Conclusion**

This study was able to capture accounts from both mothers and daughters, providing a unique and rich perspective on this issue. This was valuable in being able to observe the direction connection between mothers and daughter surrounding issues of sex, HIV/AIDS, and the quality of intergenerational communication. Most participants viewed their relationships as “close” and expressed love for the other. Moreover, both mothers and daughters displayed “protectiveness” for each other.

This “protectiveness” was displayed in various forms ranging from care-taking to avoiding the discussion of HIV altogether for fear that the other partner “can’t handle” the conversation.

However, it was evident in this sample that some level of information was being shared in regards to sex, relationships, and HIV/AIDS between mothers and daughters which is a good start to help initiate prevention strategies.

Future studies can look at how the mother/daughter relationship can be expanded to encompass other domains that affect the quality and context of the relationship, such as caregivers stress, social support, and the mothers’ sexual and drug related history, as well as barriers and facilitators of care. This study represents an opportunity for the foundation of a multi-level intervention in which both mothers and daughters are able to maximize the relationship and protect each other both physically and mentally.

## **Abbreviations**

AIDS- acquired immunodeficiency syndrome

GED- General Education Degree

HIV- Human Immunodeficiency Virus

HIV+- Positive for Human Immunodeficiency Virus

STI- Sexually Transmitted Infection

## **Declarations**

### **Ethics approval and consent to participate**

This study received IRB approval from Montclair State University and Yale University. All study participants provided written consent for the study.

### **Availability of Data and Materials**

Interview guides have been included as supplementary files. Additional study data can be obtained by request to the PI.

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## **Consent for publication**

Not applicable

## **Competing interests**

The authors declare that they have no competing interests.

## **Authors' contributions**

NAO conceptualized the study, recruited participants and wrote the manuscript. KA analyzed data, wrote and edited the manuscript. JC and FF analyzed data, wrote and edited the manuscript. WA wrote and edited the manuscript. All authors have read and approved the manuscript, and agree to its submission.

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## **Authors' Information**

Not applicable

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## Figures

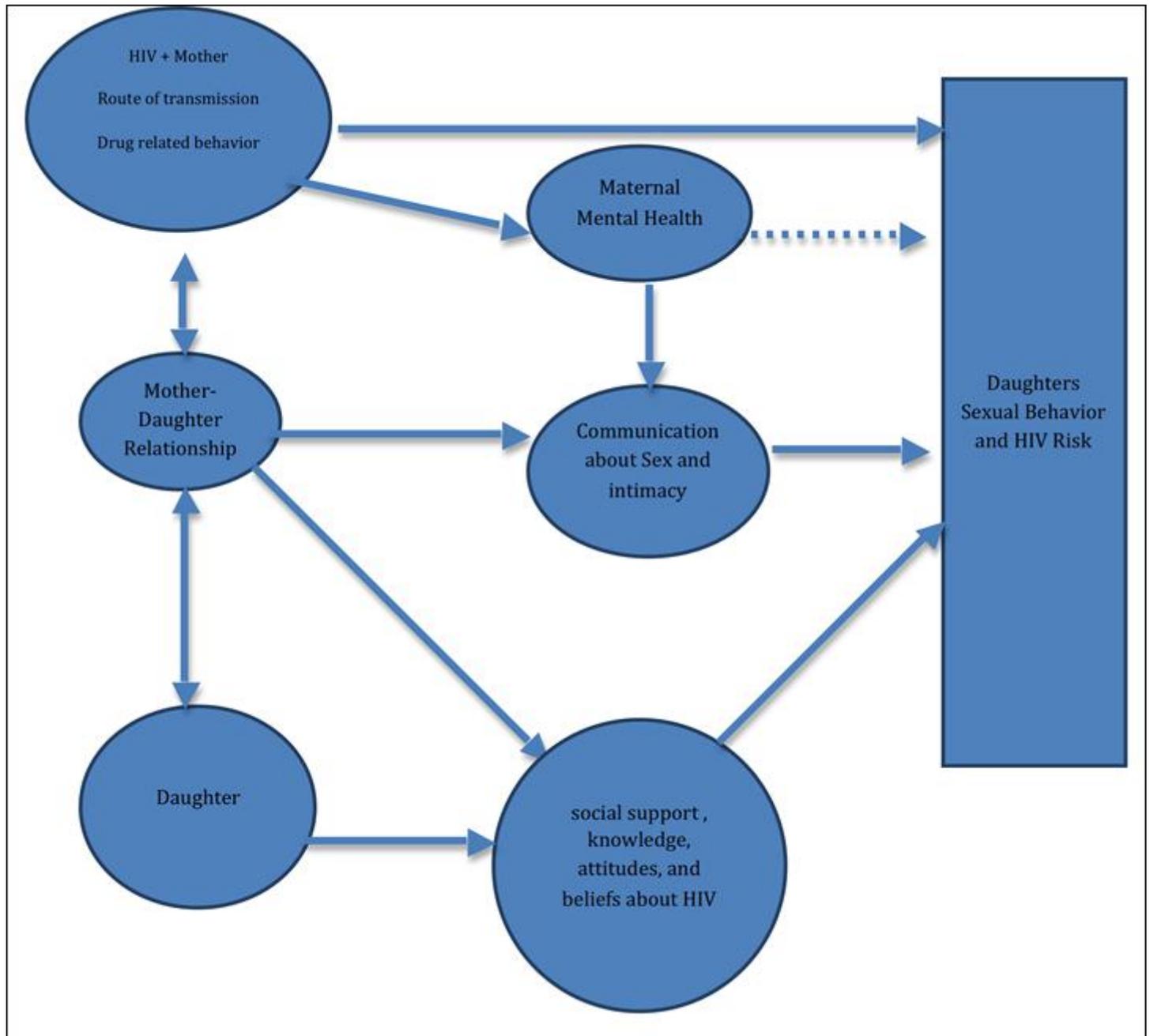


Figure 1

Conceptual model