



REPRODUCTIVE LAWS FOR THE 21ST CENTURY PAPERS
CENTER FOR WOMEN POLICY STUDIES

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HIV and Sexual and Reproductive Health in the District of Columbia
by
The Women's Collective

Introduction: The reproductive and sexual health needs of HIV positive women remain both controversial and underserved. This paper strives to refresh the current dialogue by taking stock of the current experiences of HIV positive women. The primary goal is to bring the voices and perspectives of HIV positive women in the District of Columbia to the forefront of this public dialogue. Their perspectives, expressed through a series of focus groups, shape important recommendations for advocates and professionals who work with or for HIV positive women.

Research Methodology: The research data included in this report was collected during three focus groups of one and a half to two hours that took place on Tuesday, October 25, 2011, Wednesday, October 26, 2011 and Thursday, October 27, 2011 at the offices of The Women's Collective in Washington, DC.

Focus group participants were HIV positive women over the age of 18 who were recruited over a two week period through distribution of a flyer (see Appendix I), email announcements, advertisement in The Women's Collective PLUS Newsletter, word of mouth communications, and direct recruitment of HIV positive women by Women's Collective case managers. Women expressed interest in participating in the focus groups by telephone, email and personal visits to the office of the Women's Collective. Incentives were offered to participating women, including a \$25 Visa gift card, a meal, transportation reimbursement and child care services.

The project initially hoped to reach a total of 30 women to have 10 women participate in each of the three focus groups. Ultimately, 26 HIV positive women participated (eight on October 25, 10 on October 26, and eight on October 27). The women who enlisted to participate were given courtesy reminder calls about the focus groups on both the preceding day and the day of the relevant focus groups. Upon arrival, participants were asked to sign consent forms, indicating their agreement to be audio recorded and also noting their right to abstain from participating in the focus groups.

At the beginning of each focus group, certain parameters were enumerated to govern the forthcoming dialogue. These parameters (or ground rules) took the form of a running list, created by the first focus group and expanded by the two subsequent focus groups. The ground rules included agreement to stay on topic, respect others' opinions, silence phones, maintain confidentiality regarding other participants' responses, and keep an open mind.

Participants introduced themselves to the group, using their first names only. Moderators employed a list of questions to stimulate and guide the dialogue (see Appendix II). The combination of questions asked differed for each focus group to adapt to the divergent experiences of the women present. In large part, the focus groups consisted of unregulated dialogue among the participants, with little interjection by the moderators. Each focus group was audio recorded and transcribed.

Focus Group Discussion and Perspectives: Participants addressed a range of issues of concern and their comments and recommendations are summarized below.

Defining Reproductive and Sexual Health: As the focus group moderators began designing the research project, the need arose for working definitions of reproductive and sexual health. In the spirit of placing HIV positive women's experiences at the forefront of the study, each focus group opened with a call to define reproductive and sexual health with key terms and phrases. Women volunteered different factors and procedures that they considered to be within the realm of their reproductive and sexual health. Toward the end of the focus group, this call was renewed, inviting the women to modify their initial definitions, if necessary. Below are two lists, the first of which includes women's initial definitions of reproductive health; the second list enumerates the additions that were made. No participants removed factors to modify their definitions.

Definitions of reproductive health prior to the focus group discussion included the following: a strong relationship with your obstetrician/gynecologist, comfort to ask questions of your obstetrician/gynecologist, having children, PAP smears, cervical screenings, regular visits to the obstetrician/gynecologist, intimate relationships, Mammograms, HIV viral load, safe sex, the probability of transmitting HIV to your children, physical fitness, puberty, pregnancy, and HIV medication.

Definitions of reproductive health after the focus group discussion included: drug and alcohol addiction, counseling and peer support services, financial and budgeting advice, mental health services and therapy, compassion, abstinence, hysterectomies, coordination among infectious disease providers and obstetricians/gynecologists, and prayer, faith, and spirituality.

Lack of Compassion and Bedside Manner: A number of focus group participants expressed dissatisfaction with their providers' mannerisms during their medical visits. Participants described both the difficulties associated with being unable to see a single provider and the emotional damage caused by providers' insensitivity to HIV. A common source of discomfort for HIV positive women accessing reproductive and sexual health services stemmed from being forced to repeat their experience to new providers. This anxiety was further exacerbated when women were seen by students, instead of their primary physician. This concern is particularly important for HIV positive women because their reproductive histories are laden with personal and sensitive matters and, as a result, having to repeatedly share these experiences with new providers is particularly burdensome and discouraging.

As one participant stated: "I never get to see my primary doctor, there are always students." For her, this was a problem because she had gotten "used to the primary doctor." Even more frustrating was that her primary doctor "doesn't have the decency to come in with the student to introduce [her]."

Another woman, whose provider often sends in two new doctors to see her, found it "annoying" that "they'll ask the same questions that the doctor already asked." This inconsistency in providers forced her to "search for another doctor." A third woman described a similar experience and shared her solution to the problem— she makes her appointments based on her doctor's availability because she "[doesn't] want to have to keep repeating myself over and over again."

A large majority of the women perceived a lack of compassion from their health care providers. Many respondents had received their HIV diagnosis during pregnancy and at least two respondents received their diagnoses during unwanted pregnancies. One of these pregnancies resulted from sexual violence. One woman noted that "the nurse was not compassionate." After simultaneously learning of her pregnancy and being told that she was HIV positive with six months to live, she asked: "How are you supposed to react? [...] I was just cuckoo." For this woman, the provider's lack of compassion only added to her stress and induced her to use drugs because she "couldn't get back to reality." Other participants described the cold demeanor of their providers. For example, one woman described her reaction to her diagnosis, saying "I'm in tears, [...] this is all new to me, [...] please show me some compassion." Another woman explained "I was just gone because I was pregnant, I didn't know what to expect."

One woman questioned her providers' intentions, saying that although she received appropriate care, her providers "were not too concerned about me." Instead, their focus was on treating her unborn child, leaving

her to feel like an unintended beneficiary of their services. Others complained that providers can be “very cold” and can “treat you very nasty.” One woman said that “nobody is going to take the time to sit down and talk to you” and that she would appreciate someone to sit down with her and say “please don’t be afraid and know that I’m here with you.”

Some women described even more than a lack of compassion; they felt that health care providers were casting moral judgment on their reproductive decisions. One woman said that: “Yes, a lot of doctors will give you the feeling that they’re judging you, [...] like, I don’t think you should have this baby.” Another woman felt that health care providers believed “that it’s irresponsible to be planning a child if you’re HIV positive,” especially if “you don’t have the married guy, [...] you don’t have a good job, [and] you don’t have good health care.”

Another woman’s gynecologist, after hearing that she was not sexually active responded by saying, “I think that’s a good idea that you haven’t done anything in a while [...] so you can focus on your health.” One woman characterized her experience with the gynecologist as being treated like a guinea pig. She described several doctors and students examining her vagina. Although she asked many questions about the procedure, the doctors and students only spoke with each other, ignoring her. She described being “scared” because “they didn’t explain to [her] that they were using [her] as a guinea pig to teach the students.”

Gynecologists’ Lack of Familiarity with HIV: Several women expressed frustration with their gynecologists’ lack of knowledge about HIV. These frustrations ranged from a perception that gynecologists are uninterested in HIV, to a perceived ignorance about how HIV medications interact with different methods of birth control.

One woman shared her practice of bringing information to her gynecologist because she thought it was important to let the doctor know “that you have information also.” One woman noted that her gynecologist only serves the HIV positive population while another woman hoped to “find a gynecologist who specializes in HIV.”

Encouraging Experiences: Although many of the focus group participants shared negative experiences, several women did have positive feedback to offer the group. After hearing about the negative experiences of others, one woman said that: “I’ve never had that problem where they make you feel uncomfortable; [...] I get all my questions answered.” Her providers made her “feel as comfortable as possible.” And another woman described her clinic as being “very gentle to [her]”; they made her feel “really special.” Additionally, some women felt that their gynecologist were supportive of their continued sexuality. For example, one participant consulted her gynecologist about the possibility of having children. Her gynecologist advised her that she was very fertile and could continue to have children if she wanted.

Coordination Among Infectious Disease Providers and Obstetricians/ Gynecologists: The focus group dialogue revealed a stark need for coordination between reproductive health providers and infectious disease providers. One participant expressed that initially, her HIV provider and her gynecologist did not “get along.” After some negotiation, her providers now work more cooperatively, “for [her] sake.” Some women reported very positive experiences in this regard. For example, one woman’s HIV specialist regularly asks her about her gynecological visits and requests the lab results from any gynecological tests. This focus group participant felt that the communication between her providers creates a system of checks and balances for her because it forces her to be forthcoming with both providers, because they share information. Another participant offered some advice. Emphasizing the need to be a proactive patient, she “made them [her providers] talk to each other” and “would call one [provider] while [she] was in the other’s office.”

Connecting to Counseling, Peer Support and Mental Health Services: For many HIV positive women, connection to support services can be critical, not only for psychological upkeep, but also for their physical wellbeing. One focus group participant described being “shocked” by the lack of support services she was offered after her diagnosis. She had recently emerged from an abusive relationship and, in her words, “they [her health care provider] just gave me the news and sent me out the door.”

Another woman, who received her HIV diagnosis during pregnancy, described how she “was struggling with being positive and pregnant and not wanting a rape baby, all at one time.” In addition, she was also dealing with substance abuse and “everything ate [her] up.” Another woman, who also received her diagnosis during pregnancy, revealed that she had attempted suicide three times. She was unable to terminate the pregnancy because she was nine months pregnant. In addition to struggling with her diagnosis, her mother had recently passed and the father of her child neglected both her and the newborn. Even at the time of the focus group, she remained depressed, revealing that she had not eaten in three days.

For at least three participants, counseling could have been a deterrent for substance abuse. One woman described her diagnosis experience, noting that after the provider told her she was positive, he “left out the room” without directing her to any counseling services. As she left the facility, she thought to herself “you’re getting ready to die so go ahead back out there and start using drugs, because you’re getting ready to die anyway.”

For many women, the depression that accompanies an HIV diagnosis can be paralyzing and delay their access to treatment. One woman, who received her diagnosis during pregnancy, postponed treatment for 16 years because of depression. Yet another woman received her diagnosis in 2009, but only started treatment in 2011 because she “stayed depressed for a whole year” and had to “come out of a shell to get this far.” She wishes that her health care provider had connected her to support organizations, such as The Women’s Collective, earlier.

For at least one participant, HIV support groups were educational because her peers encouraged her to use protection with her partner. Connecting with other HIV positive women prompted her to “start thinking about me.” In this regard, peer support groups can also be supplementary prevention tools, alongside condom use and other traditional prevention mechanisms.

Recommendations From Women: Focus group participants had a number of suggestions for health care providers to better connect newly diagnosed women with support groups. These suggestions include mentorship from other HIV positive women and having a therapist – or another HIV positive person -- present at the time of diagnosis. Some women felt strongly that the presence of someone more experienced with HIV would be beneficial during diagnosis because diagnosis can be “a grieving process.” One woman suggested that providers give newly diagnosed women a list of counseling and support groups, along with other services, such as food banks. She continued: “They’ll refer you to the mammogram real fast, but when it comes to mental health, they give you meds and send you away.” For this participant, the notion of patient self-management is “a nice idea,” but health care professionals “bear some responsibility to be trained” on the need for support services.

Disclosing to Children and Families: Many of the focus group participants were the primary caregivers for their children and expressed difficulty disclosing their HIV status to their children and families. In fact, many participants had not disclosed their HIV status to their children. One woman explained that “the kids don’t need to know everything.” Another woman, who had disclosed her status, described her experience, saying that “my kids are eleven and I struggled with the idea of telling them about my HIV status.” Ultimately she did disclose to her children because “it’s better for [her] to tell [her] family.”

One participant had a particularly troubling experience after disclosing her status to her family. After disclosure, she had an argument with her niece, who then stood in the hallway of her apartment building and revealed her HIV status to the neighbors. Another woman described her family as “slowly turning their back on [her]” since she disclosed her diagnosis. And one participant’s brother told her that “I don’t want to hear about it, I don’t want to talk about it.” She now feels as though her brother has disowned her.

Other participants, who had not been pregnant since receiving their diagnoses, expressed fear and anxiety about the idea of disclosing their HIV status during pregnancy. One woman stated: “If I was pregnant, I definitely wouldn’t tell them” because “I wouldn’t want the judgments.” Moreover, she wouldn’t want anyone to assume that her baby was HIV positive. She continued “I’m still having a hard time dealing with it” so, “if I was pregnant and dealing with it, there’s no way I would tell anybody.”

In contrast, some focus group participants reported encouraging experiences. At least one participant was able to find support disclosing to her eight year old son at a support center. The center offered peer support for children infected and affected by HIV. Her son met and interacted with other children whose parents were HIV positive, which allowed him to see that “he’s not the only kid with a mom that’s infected.”

Stigma Within the Broader Health Care Field: Although none of the focus group participants reported feeling stigmatized by their physicians, several women complained about stigma in other areas of the health care field. For example, one woman described her experience collecting medicine from the pharmacy: “Sometimes you can hear them whispering and making comments as you’re leaving the store.” This stigmatization adds yet another layer of stress to an already difficult experience. She continued: “No matter how we try to stay focused on our health and our wellbeing, we have to go through it, [...] first I had to get over hearing the news, then I had to get over learning that I have to take three pills for the rest of my life.” She thought to herself, “I built myself up to come to the store and you’re going to expose me like this?” This woman even described a friend who foregoes treatment because she doesn’t want to “hear the whispers” and “see the stares.” This example illustrates the need for the broader health care community to recognize that their own stigmatizing behavior deters individuals from seeking treatment and may thereby contribute to the epidemic. And at least one woman reported that she refused to seek information about having children because she feared stigmatization by the healthcare community.

Concerns for the Aging Population: As the HIV positive community ages, efforts must be made to accommodate the needs of HIV positive women beyond their reproductive prime. Although several participants no longer wished to have children, they continued to be sexual and experience the consequences of the reproductive decisions made earlier in their lives. For example, one woman received her HIV diagnosis in 1989, at the age of 23, when she was seven and a half months pregnant. Her physician recommended that she undergo a hysterectomy because future childbirth may be fatal for her. At the time, she was grappling with drug and alcohol addiction and as a result, lost custody of her children. Considering the technological advancements available today, she regrets her hysterectomy because now that she has overcome her addiction, she would like to experience motherhood. As she put it: “I do want a baby, I’m 45, it may sound crazy, [...] I want a child of my own that I can raise.”

Additionally, HIV positive women beyond the traditional reproductive age range may continue to be sexual and it is therefore imperative that health care providers continue to advise these women about their sexual and reproductive health.

Limitations of the Research Findings: Although the focus groups did reach a broad spectrum of HIV positive women, there are at least two limitations of the research findings. First, the HIV positive population is an aging population (see Appendix III for a demographic and age breakdown of the focus group participants). The aging nature of the population necessarily impacts the data collected because several focus group participants were past their reproductive primes. For many of the older participants, therefore, pregnancy was not a concern. Nonetheless, these women’s experiences are directly relevant to sexual and reproductive health because women continue to have sexual lives beyond the traditional reproductive time frame.

The second limitation regards the self-selecting nature of the focus group participants. Specifically, the HIV positive women who were able to make accommodations to attend the focus groups may be similarly able to manage their reproductive health needs. Conversely, the HIV positive women who continue to struggle with meeting their reproductive and sexual health care needs may also have had difficulty attending the focus groups. Thus, the focus group may have inadvertently excluded women who continue to face logistical difficulties in maintaining their reproductive and sexual health, such as transportation and child care.

Recommendations: The focus group results generated a series of recommendations – for policy makers, for health care providers, for community based organizations, and for HIV positive women.

Recommendations for Policymakers: An overwhelming majority of participants described the value of organizations that offer an array of services, including support groups. Policymakers can support the

reproductive and sexual health needs of HIV positive women by **increasing funding for community based organizations**, especially those organizations working in tandem with reproductive health care providers. Policy makers also should ensure **financial support for de-stigmatization campaigns**. Many women continue to struggle with stigmatization of HIV. As a result, some women may forego treatment, reproductive health care or pregnancy. By supporting de-stigmatization campaigns, policy makers can support HIV positive women, who must overcome stigmatization to access care.

Recommendations for Reproductive and Infectious Disease Health Care Providers: Many focus group participants did not seek treatment simply because they were depressed and felt isolated by their diagnosis. Providers should address this situation by **integrating counseling referral services into diagnosis**. By referring newly diagnosed women to support services, providers can not only offer psychological support to women, but also ensure that these women access care as soon as possible. Health care providers also should **provide referrals for other social services**. Many clients of The Women's Collective face difficulties in meeting their families' basic needs. Therefore, it is important for health care providers to be aware of the holistic needs of their women patients. Referrals to food banks, shelters and other support services can be instrumental in alleviating the burden of HIV on women. Reproductive and infectious disease specialists also should **connect with each other and with the patient's other health care providers** to coordinate care. In fact, many focus group participants felt a chasm between the care they received from their infectious disease provider and their obstetrician/gynecologist. Greater communication and coordination among providers may alleviate this problem.

Providers should ensure that a **counselor is available during diagnosis**. The psychological impact of diagnosis is evident from the focus group participants' responses. This impact is particularly dire for HIV positive women who are also pregnant or considering pregnancy. The availability of a therapist or counselor may mitigate this psychological impact and possibly help prevent depression. Finally, many focus group participants expressed frustration with seeing multiple providers, suggesting the importance of **maintaining continuity in providers**. Seeing a single health care provider will help to cultivate a more trusting relationship within which HIV positive women will feel more comfortable sharing their experiences.

Recommendations for Community Based Organizations: Community based organizations should cultivate partnerships with the health care community. Indeed, many women found community based support organizations to be invaluable to them as they balanced their reproductive and sexual health needs with HIV. In order to serve as many women as possible and to connect these women to peer support, community based organizations should form partnerships with the health care community and testing sites.

Recommendations for HIV Positive Women: Women should **seek out support services**, such as The Women's Collective, in their communities. As HIV positive women struggle to balance their reproductive and sexual health needs with their HIV diagnosis, it is invaluable to take part in the many opportunities for fellowship with other HIV positive women, who can offer advice, mentorship and friendship. Women also should be **pro active about accessing health care**, to ensure that health care providers serve their reproductive and sexual health needs -- and that may extend beyond your physical needs. Women can be assertive and ask health care providers for assistance in accessing all needed services, including psychological services. If necessary, women can initiate greater coordination between their infectious disease and reproductive health providers.

Appendix I: Focus group flyer

Are you HIV-Positive and
... A Mother?
... Pregnant?
... Have ever been Pregnant?
... Considering Pregnancy?
... Ever visited the OB/GYN?



The Women's Collective invites
HIV-Positive Women over the age of 18 to share your thoughts at one of our FOCUS GROUPS

☞ Lunch, Travel Assistance and a \$25 Gift Card incentive will be provided ☞
☞ Let us know if you need daycare assistance ☞

When? Tuesday, October 25th at 12-2pm, or
Wednesday, October 26th at 12-2pm, or
Thursday, October 27th at 6-8pm

(Please contact us if you would like to participate but are unavailable at these times)

Where? The Women's Collective
1331 Rhode Island Ave, NE
Brentwood Village Shopping Center
Washington, DC 20018



sharing our stories, saving our lives
www.womenscollective.org

To participate, contact Toni:
Lawfellow@womenscollective.org or (202) 483-7003

Appendix II: Focus group prompt questions

First, how do you define reproductive and sexual health?

Pre-pregnancy

1. How many people have been pregnant since their HIV diagnosis?
2. Did you consult a doctor for medical advice when you were deciding whether or not to reproduce?
 - a. Why/not?
3. Has your doctor given you any advice about getting pregnant as an HIV-positive woman?
 - a. Did your doctor voluntarily offer you this advice or did you ask?
 - b. What advice did the doctor give you?
4. Did your doctor or anyone in the doctor's office do or say anything to make you feel uncomfortable with the issue of getting pregnant?
5. Did your doctor or anyone in the doctor's office do or say anything to make you feel more comfortable with the issue of getting pregnant?
6. What steps do you think the doctor could have taken to make you more comfortable?
7. Did you have any concerns that the doctor might judge your decisions about having kids?
 - a. Why/ not?
8. Did you trust your doctor to give you all the information you needed about having children?
 - a. Why/not?
9. Did you change your mind about having kids based on your doctor's advice?
 - a. Are you happy with the decision you made?
 - i. Why/not?
10. Do you know any women who changed their minds about having kids because of their HIV status?
11. Is there any information that you wish your doctor had shared with you?
12. Are there any other thoughts or experiences that you would like to share?

During pregnancy

13. Once you became pregnant, did your doctor or healthcare provider make any special accommodations for you during your pregnancy?
 - a. E.g. daycare services, transportation, etc.
14. Did you have any difficulties meeting your doctor's expectations about taking care of yourself?
 - a. E.g. taking your medication, making your appointments, etc.
15. What concerns did you have during your pregnancy?
 - a. In the alternative, what would your concerns be if you became pregnant?
16. Were you comfortable speaking with your doctor about your concerns during pregnancy?
 - a. Why/not?
17. Did your doctor or anyone in the doctor's office do or say anything to make you feel uncomfortable during your pregnancy?
18. Did your doctor or anyone in the doctor's office do or say anything to make you feel more comfortable during your pregnancy?
19. Are there any other thoughts or experiences that you would like to share?

During and after childbirth

20. Did your doctor or anyone in the doctor's office do or say anything to make you or your child uncomfortable during childbirth?
21. Did your doctor or anyone in the doctor's office do or say anything to make you or your child more comfortable during childbirth?
22. Do you believe that you were treated differently than other patients?
 - a. Why?
23. What HIV-related services did your doctor offer you for your child?
24. Did your doctor advise you about breastfeeding?

- a. What advice did the doctor give you?
- 25. Was your doctor willing to help you get care for your newborn?
- 26. Are there any other thoughts or experiences that you would like to share?

Obstetrician/ gynecologist visits

- 27. How many people have visited the Ob/Gyn within the past year?
- 28. How many people have visited the Ob/Gyn within the past 2 years?
- 29. Does your Ob/Gyn provider discuss birth control options with you?
 - a. What information did they share with you?
 - b. Did the doctor try to steer you toward a particular type of birth control?
 - c. Did the doctor explain whether or not birth control would affect your HIV treatment?
- 30. Does your Ob/Gyn ask you anything about domestic violence?
- 31. Does your Ob/Gyn ask you anything about your housing?

Sexually Transmitted Diseases

- 32. Does your Ob/Gyn discuss your risk for other sexually transmitted diseases?
 - a. What information does your provider give you?
 - b. Does your Ob/Gyn discuss methods of protection?

Ongoing sexuality

- 33. Does your Ob/Gyn make you feel comfortable with continuing to be sexual?
- 34. Does your HIV/ infectious disease doctor make you feel comfortable with continuing to be sexual?

Recommendations

- 35. What services would have been helpful to you before, during and after your pregnancy?
 - a. E.g. information, peer support, financial assistance, etc.
- 36. What measures would you recommend doctors take to:
 - a. Make HIV positive women comfortable with their pregnancies?
 - b. Increase the likelihood that women adhere to their HIV treatment plan?
- 37. Based on your experience, what advice would you give to an HIV positive women considering pregnancy?

Defining your reproductive and sexual health, again

- 38. After this discussion, is there anything that you would add to your initial definition of reproductive and sexual health?

Appendix III: Demographic breakdown of focus group participants

Total number of participants: 26

AGE

Under 30 yrs : 0, 0%
30-40 yrs : 9, 35%
41-50 yrs : 12, 46%
Over 50 yrs : 5, 19%

RACIAL IDENTIFICATION

Black/ African American : 17, 65%
Black & Asian : 2, 8%
Hispanic : 1, 4%
Race not identified : 6, 23%

WOMEN WHO RECEIVED THEIR DIAGNOSIS DURING PREGNANCY

Women who received their diagnosis during pregnancy : 5, 19%