Adapting an evidence-based HIV prevention intervention for pregnant African-American women in substance abuse treatment

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Abstract: An adaptation of an evidence-based, woman-focused intervention designed to reduce HIV risk behaviors was conducted for pregnant, African-American women in substance abuse treatment in North Carolina. The intervention adaptation process included focus groups, expert panels, and the filming of women who spoke about their experiences with pregnancy, drug use, sex risk behaviors, HIV testing and treatment, need for substance abuse treatment, violence, and victimization. The assessment instrument was adapted for pregnant women and the intervention was organized into a 4-session PowerPoint presentation, with an additional session if a woman tested positive for HIV. All sessions and assessment instrument were installed on laptop computers for portability in treatment programs. We pilot tested our adaptation with 59 pregnant African-American women who had used an illicit drug within the past year and were enrolled in substance abuse treatment. At baseline, 41% were currently homeless, 76% were unemployed, 90% had not planned their current pregnancy, and approximately 70% reported drug use since finding out about the pregnancy. This sample of participants rated the intervention sessions and were highly satisfied with their experience, resulting in a mean satisfaction score of 6.5 out of 7. Pregnant African-American women who use drugs need substance abuse treatment that they do not currently access. Woman-focused HIV interventions help to address intersecting risk behaviors and need for treatment prevalent among this vulnerable group.

Keywords: African-American woman, HIV prevention pregnancy, drug use, violence, sexual risk

Introduction

Drug use during pregnancy continues to be a major problem, and has major implications for women and their babies who are already considered “at-risk” for HIV. Drug use compounds the risk of violence, risky sexual behavior and the inability to access social and medical services, making women and their unborn babies uniquely vulnerable.1-4 According to the 2007-2008 National Survey of Drug Use and Health (NSDUH), 5.3% of pregnant women aged 15 to 44 had used illicit drugs within the previous month.5 While the rates are lower for pregnant women than for nonpregnant women (5.3% vs 9.8%), these rates have remained relatively stable for the past decade. Taken together, these facts suggest that available treatments are not meeting the unique needs of this population.

Some studies have shown particularly elevated rates of drug-related HIV risk behaviors among African-Americans than among other racial/ethnic groups, including non-Hispanic Whites and Hispanics,6,7 consequently, there is reason to believe that this discrepancy extends to pregnant African-American women. In the 2007-2008 NSDUH,
it was found that 2.5% of all pregnant African-American women presented for substance abuse treatment compared with 1.6% of all pregnant non-Hispanic White women. Furthermore, based on our previous work in this area, we know that there are structural and treatment barriers for African-American women that make them less likely to access treatment, which means that probably there are far more African-American women who are in need of treatment than present for it. Given the public health implications of prenatal exposure to substance abuse, these data support the need for novel approaches that specifically target African-American women.

African-American women continue to be disproportionately affected by HIV than women of other racial/ethnic groups. HIV prevalence among high-risk groups ranges from a low of 1.7% among noninjecting drug users who do not trade sex to a high of 54% among homeless women who are more likely to trade sex for drugs or food. In some areas, among substance abusers in treatment, a higher percentage of people who prefer crack than those who prefer other drugs (including injecting drug users [IDUs]) are HIV positive, which may reflect that crack use is associated with increased sexual activity. Additionally, crack use has been associated with HIV infection among African-Americans in North Carolina. Consequently, the interrelationship between crack use, alcohol use, and sexual risk of HIV infection, along with trading sex for drugs and inconsistent condom use with multiple partners, places African-American women who are entering substance abuse treatment programs at very high risk for HIV infection. Further, unprotected sex potentially leads to unintended pregnancies, and national and state data indicate that African-American women have higher rates of unintended pregnancies than women of other racial/ethnic groups.

Multiple compounding contexts exist for pregnant African-American substance abusers who increase their risk of HIV infection and further contribute to their vulnerability. For example, few women are economically independent, and many report high levels of homelessness and unemployment. Education and income levels are characteristically low. Many of these women have active psychiatric disorders, some of which are the result of trauma. Involvement in crime and violence further exacerbates their predicament. These factors, coupled with low self-esteem and difficulty extricating themselves from abusive relationships, increase the likelihood that these women will engage in behaviors that place them at risk for HIV infection.

Furthermore, research has demonstrated the relationship between alcohol and other drug use and intimate partner violence, including among prenatal clinic attendees. Among pregnant women in one study, more than 80% of whom were African-American cocaine users, 70% reported emotional abuse, 34% reported physical abuse, 29% reported sexual abuse, and 42% reported personal freedom violations within the 30 days prior to their entry to substance abuse treatment. These types of violence are particularly devastating during pregnancy.

In summary, African-American women who are pregnant and substance users need comprehensive programs to reduce the risk to them and their unborn children. Evidence-based HIV interventions have been developed for African-American women, but few have targeted women in substance abuse treatment. The findings from HIV prevention research conducted with pregnant women who use alcohol and other drugs demonstrate that personalized interventions increase self-awareness of HIV risks and are more effective than generic educational interventions. This article describes the process of adapting one of these evidence-based woman-focused interventions to pregnant women in treatment programs. The intervention addresses the intersection of substance use behavior, sex risk behavior, and victimization. The adaptation process, and the characteristics of this vulnerable sample population are presented at baseline.

The original intervention

The Women’s CoOp, one of 41 “best-evidence” HIV behavioral interventions, addresses the risk around substance use, sex risk behaviors, relationships with men, social support, HIV testing, and the importance of substance abuse treatment. The core elements of this brief intervention include educational, fact-driven, woman-focused cue cards; trained peer interven tionists; behavioral skills training (eg, male and female condom demonstration and practice); role-play to improve negotiation and communication skills; and personalized risk-reduction plans (action plans). Additionally, the underlying theoretical framework of the Women’s CoOp is feminist and empowerment based, and includes a referral-based education intervention, a woman-focused and personalized action plan, and access to HIV counseling and testing. The original intervention was tested in Raleigh-Durham, NC, with African-American women who use crack cocaine.

Methods

Formative – adapting the intervention

The formative methods to adapt the Women’s CoOp intervention for pregnant women are similar to those of many studies where local and national experts are consulted, focus
groups are conducted to inform the adaptation, new topics are developed and refined, and a community advisory board (CAB) offers feedback.24 The formative phase included two rounds of focus group discussions with medical experts, service providers, CAB members, and participants from the original Women’s CoOp25 who had used crack and other illicit drugs, engaged in unprotected sex, and experienced victimization during pregnancy. The information gathered was used to adapt the “best-evidence” behavioral HIV intervention26 and other study materials to prepare for the pilot phase to determine the fidelity of its delivery and promise. Institutional Review Board (IRB) approval was obtained for this formative phase.

Four sets of focus groups were conducted with HIV-negative and HIV-positive women who were participants from the original Women’s CoOp study and had used alcohol and other drugs while pregnant. Focus group topics included substance use during pregnancy, prenatal care, treatment seeking and barriers, reasons for leaving treatment, condom use, and intimate partner violence. The notes from the focus groups were transcribed and hand-coded to identify salient themes across the groups.

As part of the women’s involvement in the intervention adaptation process, participants suggested that they offer their voices, tell their stories, and share the lessons learned in their lives to lend credibility to the new intervention. Consequently, a film company was hired, and several focus group participants shared their stories as part of short vignettes, after signing a release. Thirty video vignettes were inserted throughout the intervention to supplement the material. Table 1 presents example language used in the videos, specifically what women said about their experiences. The filming was unscripted but was edited for brevity. In addition, a new module for pregnant women living with HIV was developed with support from our medical experts.

### Adapted intervention

Overall, the newly adapted woman-focused intervention for pregnant African-American women in substance abuse treatment maintains the core elements of the original Women’s CoOp intervention,24 while adding the risk of using substances while pregnant, addressing parenting skills, victimization while pregnant, and the need for antiretroviral therapy for HIV-positive women during pregnancy; and it utilizes short vignettes from women.

The adapted intervention’s delivery is similar to the original intervention, consisting of four individual sessions (with an additional fifth session for women who test positive for HIV). Table 2 presents the overview of the adapted intervention. A peer leader from the community conducts each intervention session, which lasts approximately 45 minutes (or longer) within the privacy of the drug abuse treatment clinic where the women are enrolled. The entire intervention is PowerPoint-based and can be loaded onto a laptop computer so it is easily portable from one treatment program to another.

### Revised instrumentation

Although the Revised Risk Behavior Assessment has excellent psychometrics for African-American women,28 an adaptation was necessary to address pregnant women’s issues. With consultation from our experts, a review of the literature, and consultant input, we included new measures about prenatal care (eg, number of visits), the Alcohol Use Disorders Identification Test (AUDIT),29 and some items from the Aggressive-Acts Questionnaire (AAQ)30 and the Health and Behavioral Issues Test (HABIT).31 We also added questions on information about the father – if known – and participants’ experiences with treatment program services. We further developed and pretested an Audio Computer-Assisted Self-Interviewing (ACASI) program for privacy because of the inclusion of more intimate violence measures.

### The experimental phase

In May 2007, a small randomized clinical trial was started to measure the efficacy of the adapted woman-focused intervention compared with treatment-as-usual across multiple domains (eg, substance abuse, HIV risk, intimate partner violence, birth outcomes). IRB approval was obtained for the experimental phase.

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**Table 1** Examples of the voices of women filmed and issues they faced as part of the vignettes

<table>
<thead>
<tr>
<th>Drug risks during pregnancy</th>
<th>“When I found out I was pregnant with my last baby … I said, Lord what have I done? That baby is going to come out addicted to drugs.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment need</td>
<td>“It is so much not worth it. The high might be great. That, but when you look back … oh my one second, that 5-minute high. God, you see the whole mess of trail that you’ve made. It’s unreal. I’d say, get help. Get help, let someone help you. Just pick yourself up and try again. Don’t stay there. You know how they say you fall and don’t get up. It’s OK to fall but get back up.”</td>
</tr>
<tr>
<td>Victimization</td>
<td>“Because he knew I was pregnant, he seemed to beat on me more. As a result of the beatings and as a result of the violence, what happened was I ended up miscarrying that child ….”</td>
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</table>
We attempted to recruit participants through substance abuse treatment centers. This proved to be difficult, however, because few pregnant African-American women were enrolled in regional treatment programs. Consequently, we conducted targeted outreach, placed radio advertisements, and contacted health departments in North Carolina.

Prior to being invited to participate in the study, women participated in a brief screener to determine eligibility. Final screening was conducted before the baseline instrument in the treatment facilities or at the field site if space was unavailable. Participants had to meet the following eligibility criteria: be female, be 18 years of age or older, self-identify as Black/African-American, be between 14 weeks (3½ months) and 32 weeks (8 months) gestation (pregnancy was confirmed via biological test), self-report the use of an illicit drug within the past 12 months, be currently enrolled in a substance abuse treatment program for at least 7 days, have not been in any previous CoOp studies, and be willing to provide written informed consent and verifiable locator information for follow-up assessments. If pregnant women met all of the eligibility criteria but were not in substance abuse treatment, they were referred to a treatment center if they were interested before their initial intake appointment for the study.

Among the 96 women screened for eligibility, 37 were ineligible. Multiple overlapping reasons accounted for ineligibility, including not being interested in treatment (n = 23), not having used any illicit substance in the past 12 months (n = 21), not being within the gestation window (n = 12), and not being pregnant (n = 6). The remaining 59 eligible women from 11 treatment programs were rescreened to verify eligibility prior to enrollment and then randomized into the 2-group design. Following baseline evaluation, participants were randomized to the Pregnant Women’s CoOp intervention or to treatment-as-usual. Field staff members then conducted urine tests for pregnancy verification and a drug screen that included cocaine, amphetamines, methamphetamine, opioids, ecstasy, and marijuana. Participants also were asked to complete a 90-minute ACASI baseline interview with demographic and health questions, such as substance use, sex risk behaviors, experiences with violence, and prenatal care.

This article presents only limited baseline characteristics and satisfaction with the intervention. Descriptive analyses were conducted on key baseline variables in SPSS 17.0 for Windows (SPSS Inc., Chicago, IL), and differences between treatment groups were analyzed. Intervention satisfaction was measured post-intervention with a 7-point rating of yes-no analyzed with some open-ended questions pertaining to

<table>
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<th>Table 2 Overview of intervention sessions</th>
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**Session 1**
- Welcome and introductions
- Being healthy and pregnant
- Beginning this process: 5 Rs for risk reduction
- Staying in treatment
- Drug risks during pregnancy
- Benefits of substance abuse treatment
- The bottom line
- Action plan

**Session 2**
- HIV among African-American women in NC
- What is HIV?
- Other sexually transmitted infections (STIs)
- How can untreated STIs affect a woman and her baby?
- Importance of using protection
- How to use male and female condoms
- Healthy vaginal practices
- Oral sex
- Sex trading and “taking care of business”
- Injecting drug users (if applicable)
- Talking about safer sex
- Negotiation and effective refusal
- Stay alert, stay powerful
- Action plan

**Session 3**
- Substance use and relationships
- Victimization and abuse
- Violence prevention
- Staying safe
- Know your rights and don’t give up
- Physical effects of violence during pregnancy
- Prenatal care
- HIV test
- Action plan

**Session 4**
- The HIV test – reminders
- Understanding relapse
- Benefits of a drug-free life
- Suggestions for building a sister-to-sister network
- Building your personal power and confidence
- Summary: 5 Rs for risk reduction
- Community resources for women
- Substance abuse keeps you oppressed – empowering yourself
- Assertive and powerful women
- Action plan

**Session 5 (for HIV+ women)**
- Being HIV+ and pregnant
- How HIV affects the immune system
- Factors that may increase the risk of mother-to-child transmission
- Is breastfeeding best ... not necessarily
- Anti-HIV drugs – protect you and baby
- Viral load and CD4 count
- Adherence and drug resistance
- Anti-HIV drug safety
- Hepatitis C
- Tuberculosis
- Good nutrition
- What type of medical follow-up should you consider?
- Action plan
satisfaction with staffing, information presented, vignettes, and other intervention components.

Results

Formative

Reaching women from the target population yielded key information about barriers to treatment. For instance, participants shared important information about sensitive issues, such as their experiences with racism. One participant shared that she was told, “get your nigger ass on the table” while receiving prenatal care.

Traditionally, women who use alcohol and other drugs have not engaged in substance abuse treatment because of the fear of losing custody of their child.32,33 For this reason, programs serving this population have stressed the importance of allowing women to bring their children into treatment with them. Women who participated in this study agreed they “needed a caring system,” one where the healthcare providers care about the women and do not discriminate against them. One participant stated that, “Black women are very sensitive to people’s [negative] attitudes. If they detect any attitude or discrimination toward them, they will cop an attitude, give the discriminator a hard time, and will also not return.”

The majority of the women in all of the focus groups addressed partner violence as a missing component in the original Women’s CoOp intervention. They agreed about being more victimized when pregnant: “The women can’t fight back. They’ll punch you right in the stomach while you’re pregnant. Men will beat you because they think you have been with another man. They will beat you down for your money; because they want half if not all of the money you get from welfare or from the streets. Men will beat pregnant women in public and no one will help.” Many of the women knew other women who had miscarried because of partner violence. This confirms prior research that pregnancy is not a protective time for substance-using women.

An important suggestion for getting women to stay in treatment was that mothers need to have access to childcare, and they need to have a plan for after the baby is born: “They need to know who’s going to be taking care of the baby.” Often, the older children are taking care of the younger children and none of them are being supervised. Children who are raised in this environment often get involved in drugs, sex, and violence at a very early age, and the family cycle of addiction continues.

Most of the women expressed the desire to take care of their children; however, one woman seemed indifferent to having her children with her. It is unclear whether some of these babies are born displaying withdrawal symptoms of irritability and poor attachment behavior or whether their mothers’ are misreading cues and being nonresponsive. A body of research exists about this dynamic, as prenataly exposed babies who suffer protracted withdrawal may fail to respond in the usual ways to a mother’s comfort (ie, fail to mold and cuddle). Unfortunately, this may be interpreted by the mother as rejection, and then she may respond in kind.

Experimental

Table 3 presents the self-reported baseline data from the women and admitted substance use (about 70%) since knowing of their pregnancy. Some women were multiparous and most (89%) had not planned this pregnancy. A sizeable percentage of the women reported being homeless (40%), and 15% reported victimization since being pregnant. At baseline, overall 28.8% had a positive drug screen, with 12 (20.3%) testing positive for cocaine and 11 (18.6%) testing positive for marijuana (data not shown in table). No significant differences were found between the intervention and treatment-as-usual groups on the variables presented in the Tables 3 and 4.

Table 4 presents self-reported drug use in the 90 days prior to baseline interview. Some women had been in treatment for different periods of time (mean of 42 days, SD 62.6), (data not shown in table) showing varied rates of positive biological drug screening at baseline, although substance use continued
Table 4 Self-reported drug use and sexual risk in the past 90 days

<table>
<thead>
<tr>
<th>Self-reported characteristic</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance use in the past 90 days</td>
<td></td>
</tr>
<tr>
<td>Tobacco</td>
<td>74.6%</td>
</tr>
<tr>
<td>Marijuana</td>
<td>50.8%</td>
</tr>
<tr>
<td>Crack</td>
<td>52.5%</td>
</tr>
<tr>
<td>Alcohol</td>
<td>42.4%</td>
</tr>
<tr>
<td>Sexual risk in the past 90 days</td>
<td></td>
</tr>
<tr>
<td>No. of sex partners, mean (SD)</td>
<td>8.0 (36.8)</td>
</tr>
<tr>
<td>No. of unprotected vaginal and/or anal sex acts with main partner, mean (SD)</td>
<td>16.6 (24.4)</td>
</tr>
<tr>
<td>Sex trading</td>
<td>38.5%</td>
</tr>
</tbody>
</table>

Note: No significant differences were found between the intervention and treatment-as-usual groups on the variables presented.

whether in treatment or not. The treatment programs were a mix of outpatient and residential care. These women also reported multiple sex partners, unprotected sex, and sex trading while pregnant.

**Intervention feedback**

The adaptation and pilot test also included feedback from participants and ratings of their satisfaction with the Pregnant Women’s CoOp intervention, which were measured at various intervals. A sample of 24 forms were completed on intervention satisfaction, with a 7-point rating scale and analyzed with some coded open-ended questions. The mean score was 6.5 (SD 0.51), demonstrating strong positive satisfaction for the intervention. The majority of the women in the intervention sessions reported that it was helpful to hear other women’s stories. Some representative responses about what the women remembered about the intervention or what was helpful for them include the following:

- “The ladies [sic] on the video and how they overcame their addiction [sic].”
- “The woman [sic] who share there [sic] story made me feel good about helping myself.”
- “The video stood out the most to me.”

**Discussion**

Developing an intervention for African-American women who are pregnant and in substance abuse treatment at a time when they are a group most at risk for HIV is innovative and essential. Women from the community were part of the intervention’s development and became voices of the intervention. The participants who provided feedback were overwhelmingly supportive.

While this project aimed to reach women in substance abuse treatment with a portable intervention, most of the participants were not found in treatment centers. One notable limitation of this trial involves reaching women from numerous treatment facilities in North Carolina. Consequently, it is difficult to generalize the study findings beyond these study participants, specifically. However, the adaptation of the evidence-based intervention sets the stage for others to use it and for it to be used in additional settings and to engage a larger population of at-risk, pregnant, African-American women.

The barriers to treatment as well as the racism and stigma experienced and expressed by these women may reflect some aspects of the underlying Southern class system. Poor African-American women who use drugs are sometimes isolated by society and often lose their children to the department of social services; and they feel this negative attitude and often lack any positive social support. In this sample, most of the women had not planned these pregnancies, yet they chose to keep these babies despite being unemployed and a large proportion of them being homeless. However, although these women were pregnant, many chose not to go for substance abuse treatment, for fear of losing the child. Yet, with extra guidance they were able to enter a program and receive care and support. Part of this success may be in the use of peer leaders, especially in part of this intervention, who were inspirational role models for these women, making it difficult to disentangle participants’ commitment to treatment.

Women can be motivated to change their behaviors when they are pregnant, but often fall short. During the formative stage of the study, women in our sample talked about how women need to have a plan for their child, as well as the need for treatment centers to be sensitive, supportive and caring, with adequate childcare. Of the sample, 50 women (85%) were followed up 6 months post-enrollment. A paper presenting the treatment effects is currently in press. The future treatment and risk reduction methods for these women needs to take into account their voices and be women-friendly and sensitive to certain aspects of women’s lives, including childcare. Offering ancillary services has been shown to be an important aspect for women’s success in substance abuse treatment. Economics plays a part in what programs can offer in this time of shrinking funding. It may be difficult for community programs to reach pregnant minority women, who may be hesitant to come into their systems because they do not have outreach staff or case managers available, or childcare staff. However, if programs want to reach the most vulnerable women, they will need to be creative with staffing, such as interns and students, to help offer services desperately needed to bring women into treatment and to address their intersecting risk factors.
Acknowledgments
This work was supported by the National Institute on Drug Abuse (NIDA) under grant number R01 DA020852. The interpretations and conclusions presented in this article are solely those of the authors and do not necessarily represent the views of NIDA or the US Department of Health and Human Services. We wish to thank all our project site staff, treatment programs, and the women participants who made this possible. We also thank Jeffrey Novey for his editorial support and Larry Kroutil for his assistance accessing pertinent SAMSHA data. The ClinicalTrials.gov number of the experimental phase is NCT00722670.

Disclosure
The authors declare no conflicts of interest.

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