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HIV, STD and hepatitis prevention among women in methadone maintenance: a qualitative and quantitative needs assessment

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Abstract *In the USA, as well as internationally, rates of HIV infection among women continue to grow. In addition, women who inject drugs are at further increased risk for hepatitis C co-infection. The purpose of this study was to conduct qualitative and quantitative needs assessments for HIV/STD/hepatitis prevention among women in methadone maintenance programmes. Qualitative interviews and a quantitative, self-administered questionnaire were used to develop an understanding of their needs, and perceptions of what they believed would constitute effective prevention intervention programmes. Results supported women's interest in these services and provided feedback on how to structure prevention programmes by placing them in the context of women's lives and addressing concrete barriers (e. g. transportation, child care, confidentiality concerns) to facilitate adherence to these programmes. Respondents indicated a desire for HIV prevention information, but also wanted information on hepatitis, relapse prevention, stress management and accessing services. The development of such programming would require partnering with the target population and their service providers to develop feasible and effective interventions.*

Introduction

Women represent the fastest growing segment of the HIV-infected population, accounting for approximately 30% of new HIV infections annually in the USA (CDC, 2002a) and approximately 50% of HIV/AIDS cases globally (UNAIDS, 2002). Injection drug use (IDU) accounts for approximately 25% of new HIV infections (CDC, 2002a) and HIV prevalence among women entering drug treatment was approximately 14% in 1997 (CDC, 2002b). Approximately 1.8% of the US population is infected with the hepatitis C virus (HCV), with the majority of these infections the result of injection drug use (CDC, 2001; Phillips & Brewer, 2003; Zdilar *et al*., 2000). Due to similar routes of transmission, those at

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risk for HCV are also at risk for HIV and other strains of hepatitis (CDC, 2001). Thus, women with histories of injection drug use face numerous health-related risks.

Baker and colleagues (2001) found that women enrolled in methadone maintenance continue to engage in risky behaviour, both drug-risk behaviour (e. g. polydrug use, injection drug use) and sexual risk behaviour. Effective interventions are needed to address these ongoing risks. Methadone maintenance is an effective treatment for opiate addiction, and one which decreases HIV risk by reducing the frequency of illegal, and often unsafe, injection behaviour (Baker *et al*., 2001; Jones *et al*., 1994). It seems prudent, then, to combine HIV prevention interventions with such treatment programs. In a survey of 164 methadone users, Jones and colleagues (1994) found that participants described an 'ideal' methadone programme as one with services related to HIV education (91%) and counselling (85%), including: testing (73%), condom provision (73%) and group interventions (72%). Clearly, this population is aware of their risks and open to using methadone programmes as venues for addressing them.

According to Ehrhardt and Exner (2000), effective programmes for at-risk women involve multiple, sustained contacts and address negotiation and relationship skills. Exner and colleagues (1997) previously recommended that prevention efforts emphasize individual, relational and environmental factors that impact risk, incorporate skills-based interventions that are gender- and culture-specific, and address risk reduction strategies women find acceptable within their framework of sexuality and relationships.

Little has been done since to apply these findings to the population of women in methadone maintenance. We designed a study to evaluate the effectiveness of such a risk reduction intervention to this population, using the recommendations of Exner and colleagues (1997) and Ehrhardt and Exner (2000). The project was implemented in a methadone maintenance programme in Rhode Island. Despite basing the intervention on empirically- and theoretically-sound concepts, and in the context of a seemingly great need, the project faced great difficulty in recruiting and retaining participants. In response to these difficulties, the goal of the present study was to partner with women in methadone maintenance to develop an intervention that fit their needs and their perceptions of what makes an effective intervention. We conducted qualitative and quantitative needs assessments with women in methadone maintenance programmes throughout Rhode Island to meet this goal.

Methods

The first phase of the study involved collecting qualitative data from women in one of the largest of eight urban methadone maintenance programmes in Rhode Island. Focus groups and interviews were conducted with a total of 30 women, aged 18 and older. Ten participated in focus group discussions, four participated in dyad interviews and 16 participated in individual interviews. The decision on type of interview for a participant rested on her availability in scheduling and comfort in addressing the issues to be discussed (i. e. some women felt uncomfortable discussing sexual or drug use data amongst peers in a substance abuse programme; others wanted their HIV, STD or hepatitis status to remain private, so requested an individual interview). Data were collected by two doctoral level psychologists and a research assistant (RA) trained in qualitative methodology. The interviews assessed the acceptability of prevention programming including: health topics of interest, preferences for programme features including type of session, type of facilitator, session duration and

frequency, barriers/facilitators to participation, and recommended recruitment/retention strategies.

The second phase of this research involved the completion of a 33-item self-administered questionnaire by women in all eight methadone maintenance programmes across Rhode Island. This measure was developed based upon the results of the qualitative data, to follow-up on topics participants identified as important in acceptable prevention programming and gain a broader sample more characteristic of women in methadone maintenance throughout the area. An RA distributed the questionnaire to participants, provided instructions on how to complete the instrument, and was available for questions.

Data analysis

All focus groups and interviews were audiotaped. Tapes were transcribed and reviewed by the facilitators for accuracy and completeness. The transcripts were analyzed and coded to identify themes that emerged from the data regarding the need for and expectations of prevention programmes. One-half of the transcripts were double-coded (coded by two researchers) to ensure accuracy and concordance in coding. When complete concordance (100% agreement) was reached, one researcher completed the coding of the remaining transcripts.

The quantitative data were entered into a statistical database. The data were double entered to ensure accuracy, and reconciled when necessary. Analyses on the quantitative data were run through a statistical software package (SPSS). Simple descriptive statistics were run to provide information on the distribution of responses.

While the qualitative interview data were collected first in service to the development of the questionnaire, in reviewing the data in its entirety, we believe the qualitative data also serve to illustrate the data compiled via the questionnaire: as such, the quantitative data will be presented first for a more global perspective and the qualitative data will be used to illustrate those results.

Results

One hundred and twenty-three (123) women completed the questionnaire (72% response rate). The mean age of questionnaire participants was 39.7 years (range = 24–70 years, SD = 7.7). They completed an average of 11. 4 years of education (range = 5–17 years, SD = 2); 86 (70%) of the participants had a high school degree or its equivalent, and higher. The participants reported an average of 16. 8 years of drug use (range = 1–37 years, SD = 8. 6) and participation in their current treatment programme ranged from 0 to 190 months (mean = 37 months). The sample included white (78%), Hispanic (7%), black (6%), American Indian/Alaskan Native (2%), Cape Verdean (1%), biracial/multiracial (4%) and 'other' (2%) women. Their relationship status included: never married (34%), married (16%), living with a partner (9%), separated (11%), divorced (23%) and widowed (7%). Self-identified sexual orientation was reported as heterosexual (89%), bisexual (8%) and homosexual/lesbian (3%).

Health topics of interest

Information on hepatitis was a key interest reported by 56% of the participants in the quantitative survey. Qualitative data highlights this:

> Well, I got tested positive for hepatitis C so that's one of my strongest issues for health care. I don't know what to do.

> Well, one thing that's really important to me is hepatitis C, 'cause I didn't know that you could catch it [even] if you bleached your syringe.... I found out too late. I just cleaned my things with bleach. They belonged to somebody else that, you know, that I knew really well and I still ended up with hepatitis C. So, I think educating people about hepatitis C because it's in epidemic proportions now...

The second most popular topic was relapse prevention (55%):

> What's important is staying clean and staying healthy and maintaining your sensibility and your outlook, your attitude...you can focus on your lifestyle, your family and try to better yourself on your life to come.

Information about HIV prevention followed (51%), with information about STDs and their prevention less frequently cited as important (29%):

> Condoms, they need to know how important it is.... AIDS is still here, you know you still die from it, you know what I'm saying? ... I don't know what they're thinking but there are still people just sleeping around and not using no kind of protection and they think that it's ok and it's not ok...

> The general health issues...especially a lot of people [who] have worked in the sex industry...people who have herpes don't even know that there's something that they could take so that they don't have multiple outbreaks...

> Participants also expressed interested in topics beyond HIV/STD/hepatitis

prevention, including stress management (42%):

> [Health topics may not be on the top of people's list] But I think if they came in for something like...you know, their stress problems or their mental and emotional...state. [They might be likely to keep coming if you address] psychological wellbeing and then everything else maybe, because certain things that affect us more...we tend to be more interested in...

accessing services (23%):

> ...when you say health prevention, I mean really, how many people have health care? ...women who have children probably have [state-funded insurance]. Single women, professionals, para-professionals, you may have it or not.... You've got, well, yeah, because you can give people information on where to go for certain things but are these free services? Is there a cost involved? ...you go see a doctor and they write a prescription for...the most expensive antibiotic...the doctor says well what do you have for medical coverage? Well I have nothing. Oops, well you can't get the medication...

and learning about methadone and its effects (18%):

> Well, the effects of methadone as far as coming off heroin and...methadone. Methadone is much more traumatic and of longer duration and you're not informed of this upon entering...[you] find out in the long run...I think that maybe people should be warned...

Intervention format

Participants were asked their preference for intervention format. A combination of group and individual sessions was endorsed most frequently (45%), followed by group sessions alone (38%), individual sessions alone (14%) and dyads, that is two peers/friends and a counsellor (3%). The preference for the combination group and individual intervention was explained:

> Some people are comfortable in groups, others are not, everybody is different. . .offer both.
>
> I might be in a group this week and then each person may be. . .assigned a one-on-one person they could have an appointment with. . .when people have certain things that they didn't talk about in group. They can make an appointment to see [a one-on-one counsellor], you know. Something they want to really get out, you know. That would be a good option to have and it would be connected to the group, it wouldn't be so much like just having a drug counsellor.

Facilitator preference

Participants were asked whether they would prefer an intervention be conducted by a professional staff member (48%), by a trained peer or near-peer (6%) or by co-leaders, including a professional staff member and a trained peer or near-peer (45%):

> I think it would be better coming from a doctor. . .they know more about it than anybody.
>
> Go to all different parts of towns. Go to the projects. . .it has to be [a] woman that been through. It can't be women that you know come from a well-to-do family and read the textbooks. . .. [Be]cause that's not making it. . .. When they say well, how do you know, what did you do, what happened to you? And they can say, yeah well I used to do this, that and this, they'll listen to that first. . .. But if they're like well I've been to school and I know from the book. . .. Right off the back they're gonna totally ignore you. They're gonna say, oh you don't know, you've never been through this.
>
> But it has to be. . .that they got somebody they can recommend that person to. Meaning that I know I'm safe with this here: that even if she can't deal with this today, . . .she can connect me to somebody who can take care of what I really have needs for.
>
> Nothing is more powerful than peer led. Anything, as long as the peers have the right information. . .but, it's always good to have a credentialed health care provider there because I'm sure, there's always a question that you don't know the answer.

Number/length/frequency of sessions

Participants were asked how many sessions an intervention should include; 51% expressed a preference for an intervention consisting of two–four sessions, while 37% preferred one consisting of six or more sessions, and 5% preferred a single-session intervention. As for how often sessions should be scheduled, the participants were about equally divided between weekly (32%), every other week (32%) and monthly (31%). However, participants largely agreed that sessions should run for 60 minutes (61%), with only 7% expressing a preference

for sessions lasting longer than 60 minutes. Their preference for sessions lasting 60 minutes or less were explained as follows:

> At least an hour. I think that any shorter than an hour, you really hope you get the issues out and discussed. . .. If there's something that's really important that's gonna take a while and it's a big group.

> I think like 45 minutes is good; they start wanting an hour, hour and a half and people start getting distracted. You get tired of sitting there with people you don't know. . .if you start going too long then it's, 'I'll go off somewhere in my head where I ain't even listening to you no more.' So it's kind of a waste of my time and your time, you know. . .. Especially when you're first trying to get clean and stuff, you know what I mean?

Barriers to attendance

Participants identified concrete barriers to participation in programmes, including transportation (61%):

> A lot of people don't [have a car] and travel was a big problem. . .when my car wasn't running I couldn't get here.

scheduling conflicts (49%):

> 'I have like fifty million appointments between me and my daughter and my grandmother, it's. . .hard to remember. . . those appointments. . . If they were around the time that I get dosed then it would be easier. . .. You have to come here to get dosed.

and child care (34%):

> 'Child care is somewhat of an issue. . .. Now it would be nice if they had another room [with] a volunteer service in the other room with the kids.

> It's hard to leave [after being dosed] and come back [for a programme] and to keep finding someone to watch the kids.

Participants also reported less tangible barriers to participation. These included concerns about confidentiality (34%) and trust (33%):

> Some people wouldn't want to [go to group] because they wouldn't want other people to know what they're talking about.

> I'll say some things in a group but I'm not gonna bare my soul to [them] either. [Be]cause I know how the people are that are in there and I'm gonna see them out in the street; you're not gonna say too much stuff in front of them.

Facilitators to attendance

Participants identified factors that would help them attend prevention programmes including: interesting topics (75%), incentives (63%), feeling better about themselves by attending (62%), finding support helpful (54%), trusting the leader (49%) and other participants (45%), learning new skills (48%), having attendance count toward earning 'take-home doses' (38%) and liking the other participants (37%) and the leader (36%).

Women suggested that it is helpful if the facilitators take an active role in getting people into sessions:

> [Be]cause a lot of people don't like to go to the group.... But... you got to be pushy...and make sure you know today's the group and you just got to be there and make sure you grab them.

> People don't want to give you their time unless you're giving them something; they don't realize you're giving them an advantage over everybody else that don't know half of what you're learning.

Recruitment and retention strategies

When asked to suggest recruitment strategies, participants suggested: flyers (86%), methadone counsellor referral (76%), being approached by prevention programme staff in person (75%), word of mouth (66%), 'soft hold' (i.e. having to check in at dosing time with methadone maintenance staff to learn about the programme, but not having their dosing impacted by this notification) (58%) and dispersion of business cards (55%).

In order to help women attend sessions and complete a programme, participants suggested: giving reminder phone calls one–two days before a scheduled session (84%) or on the day of the session (47%), sending a reminder letter one week before the session (79%), placing participants on 'soft hold' one–two days before the session (59%) or on the day of the session (54%), sending a reminder letter to friends/family members (27%) and making a reminder phone call to friends/family members (35%).

Discussion

Women in methadone maintenance programmes, widely recognized as being 'at-risk', are indeed interested in HIV/STD/hepatitis prevention services, confirming the findings of Jones and colleagues (1994). What is powerful about our results is what they tell us about how this population feels able to approach the topic of HIV and STD prevention. Participants clearly indicated that a narrow focus does not meet their needs, and that *hepatitis* prevention is a key health concern (Zdilar *et al*., 2000). Beyond strictly physical health issues, participants cited relapse prevention and accessing necessary social services as significant topics. The data identify concrete barriers that must be addressed to provide an effective intervention, such as childcare and transportation. Further, significant attention to issues of confidentiality and trust must be paid in developing and implementing effective prevention interventions with this population.

Just as Ehrhardt and Exner (2000) indicated that HIV prevention interventions should consist of multiple and sustained contacts, our participants endorsed use of both individual and group sessions. This combined approach allows participants to receive the benefits of both individual attention and feedback, and the support of a group of peers. Using a combined approach can assist in the dissemination of information, enhancing motivation and building behavioural skills within the context of an individual participant's life, factors key to effective HIV prevention (Fisher & Fisher, 2000; Miller & Rollnick, 1991).

Effective interventions must be developed in partnership with the potential recipients of that intervention. Although our initial project was based on 'state of the art' empirical and theoretical models of HIV prevention, it did not generate enthusiasm and support in its

audience. What was missing was a partnership that brought the target audience into the planning of the project, placing its HIV prevention message within the context of other priority areas in their lives. Future prevention efforts should include both sound theoretical considerations and an assessment of the needs and feasibility of a programme designed in partnership with the target population.

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