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FACTORS INFLUENCING CONSENT TO HIV TESTING AMONG WIVES OF HEAVY DRINKERS IN AN URBAN SLUM IN INDIA

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Abstract

The study examined the influence of socio cultural factors, perception of risk and exposure to violence on consent to HIV testing among at risk women in an urban slum. Married women chosen via a multistage probability sampling in a section of Bangalore, India, between 18 and 44 years, sexually active and considered to be at risk because of their husband's hazardous drinking were recruited for the study. Written informed consent was obtained and measures of risk behavior and violence were administered. Pretest HIV counseling was then conducted and consent for HIV testing was sought. Factors influencing refusal of and consent to HIV testing were documented. Data collected on 100 participants indicated that over half the sample (58%) refused consent for HIV testing. There were no significant differences between the groups who consented and those who refused on perception of risk and exposure to violence. Reasons women refused testing include the following: spouse/family would not allow it (40%), believed that they were not at risk or would test negative (29%) and underwent HIV testing during an earlier pregnancy (21%). Among those who consented for HIV testing, 79% did so because the testing site was easily accessible, 67% consented because testing was free and because the importance of HIV testing was understood. The findings highlight the role of social, logistic and awareness related factors in utilizing voluntary counseling and testing services by women in the slum community. They have important implications for HIV testing, particularly among at risk monogamous women.

Keywords

HIV testing; Community Based Prevention; Consent; India; Women

INTRODUCTION

Community based voluntary counseling and testing (VCT) services play an important role in HIV prevention (NACO, 2004; WHO, 2007). However, lack of awareness, stigma and discrimination often restrain people from utilizing VCT services (Baiden et al, 2007). Consent rates for voluntary HIV testing vary across cultures and settings, with consent rates in developing countries being lower than that of developed countries (WHO, 2006). However, in both developing and developed countries, consent rates in sexually transmitted infection (STI) clinics and antenatal settings seem to be higher than in community settings (WHO, 2006). Recently, in order to scale up HIV testing rates, CDC and WHO have introduced routine testing, opt out HIV testing policies and elimination of written informed consent (CDC, 2006; WHO, 2007). While these are likely to enhance the uptake of HIV testing (WHO, 2007), other factors that deter or motivate an individual to test for HIV, need to be elucidated as well.

Literature, albeit scarce, indicates that several individual and contextual factors influence refusal to HIV testing. A study in Pittsburg showed that consent rates for HIV testing were low. Common reasons for refusal were denial of risk and fear of testing positive (Moyer et al, 2007). Similarly, avoidance of HIV testing was found to be related to psychological issues (Lyter et al, 1987), fear of increased stress and suicidality (Lemp et al, 1994), fear of being

tested and of receiving the results (Johnson et al, 2001), discrimination (Speilberg et al, 2003), and concerns about anonymity and confidentiality (Jackson & Hafemeister, 2001).

HIV testing services provided free of cost in a convenient and easily accessible testing site motivated over two thirds to undergo HIV testing in rural communities of Northern Thailand (Kawichai et al, 2007). Free VCT services enhanced both the number of clients tested per day and its cost-effectiveness in resource-limited settings of Northern Tanzania (Thielman et al, 2006). However, readiness for VCT in the general population has been found to be low. Concerns about confidentiality and waiting time for test results affected low utilization rates in Zambia (Fylkesnes et al, 1999).

People who refused testing had higher seropositivity; the principal reason for refusal was denial of risk. The principal reason for consenting was desire to know the results to benefit self and prevent the spread of the virus to partners (Jones et al, 1993; Killewo et al, 1998). People younger in age with higher levels of education were more likely to consent to HIV testing compared to older people with lower levels of education (Ole-King' Ori, 1994). Willingness to undergo HIV testing was also associated with previous HIV testing, better knowledge of HIV and lower perception of stigma and discrimination (Zhang et al, 2007).

Further, although women in monogamous marriages perceived a low risk of contracting HIV, these same women also lacked the power to negotiate and feared offending their husband (Taegtmeier et al, 2006). In a recent study of women attending an HIV VCT centre in Bangalore, India, 42% reported exposure to violence. Among them, 67% reported being HIV positive (Chandrasekaran et al, 2007). Studies in the West and in India have demonstrated a positive relationship between substance use, sexual risk behaviors, partner violence and subsequent risk for HIV (Collins et al, 2005; Schensul et al, 2006; Sivaram et al, 2008). The impact of high risk behavior and exposure to violence, on consent to HIV testing merits further study.

Thus, it appears that a complex set of individual and structural factors influence consent to HIV testing. An understanding of these factors is essential to bridge the gap between service delivery and utilization. Furthermore, it is evident from the published documents of the National AIDS Control Organization (NACO) and an online Pub Med search, that there are no Indian studies related to issues of consent in HIV testing. The present study, therefore, attempted to explore factors influencing consent to HIV testing among at risk women in an urban slum in India.

METHOD

Participants

Data for these analyses come from the World AIDS Foundation (WAF) funded community based HIV prevention study for at risk women in an urban slum in Bangalore city, India. 'At risk women' was defined as wives of heavy drinking men (Parikh, 2007; Smith, 2007). Eligible women were between the ages of 18-50 years and married to a heavy drinking spouse [scored 8+ on Alcohol Use Disorders Identification Test (AUDIT)]. To identify heavy drinking men in the slum, 509 households were enumerated. First, a complete listing of residents of a household was obtained and the youngest married male in the household was screened for heavy drinking. The field staff identified 186 heavy drinking men. From these men, the first 100 wives were approached. The interviewers met with the women in private at the Primary Health Centre (PHC) within the community, and sought their participation in an HIV prevention research study. Women were told that the objectives of the study were to increase awareness about HIV, STD's and substance abuse and mental health problems, and to help them protect themselves and their family from HIV. Written informed consent was obtained

and interviews on substance abuse, mental health problems, risk behaviors and exposure to violence was conducted. After the baseline assessments, women were randomized either to the standard intervention group [HIV pre and post test counseling based on NIDA and National AIDS Control Organization (NACO) guidelines] or to the enhanced intervention group (standard + one educational group intervention session on health, nutrition, stress and coping). All the 100 women were followed up after 2 months to test the effectiveness of the intervention (100% completion). For the purpose of the present analysis, only baseline data are presented.

The study was approved by the Institutional Review Boards of Washington University School of Medicine, St. Louis, the National Institute of Mental Health and Neuro Sciences (NIMHANS), India and the Indian Council of Medical Research (ICMR). As per NACO requirements pretest HIV counseling was conducted individually, following which, a separate written informed consent for HIV testing detailing the procedure and possible risks and benefits was sought. For consenting participants, blood samples collected by a trained staff nurse were tested for HIV using the ELISA test. All participants received remuneration, in the form of refreshments, for their participation in the study. Irrespective of the test result, post-test counseling was offered to all women who consented for HIV testing.

Measures

Factors influencing consent versus refusal were assessed with the HIV-Reasons for Consent Form (HIV-RCF). The HIV-RCF was developed for the purpose of the present study in order to document reasons for consenting versus refusing HIV testing. The HIV-RCF was prepared based on existing literature and prior experience about common reasons motivating consent versus refusal of HIV testing in the community. Reasons for not undergoing HIV testing (refusal) as well as reasons for testing for HIV (consent) were elicited using two open ended questions: "What were the possible reasons for not undergoing HIV testing?" and "What were the possible reasons for having the HIV test? For each of these questions, 7-8 response options were listed and the participant was told to indicate whether or not each option applied to them. These response options could broadly be classified as 'social', 'logistic' and 'awareness related' factors. The items in HIV-RCF yield categorical data; the responses were analyzed by computing frequencies and percentages.

Risk behavior was assessed with a modified version of the Washington University Risk Behavior Assessment for Women (WU-RBA-W). The original Risk Behavior Assessment was developed by NIDA for use in the Cooperative Agreement studies (Needle et al, 1995). The RBA has been shown to have excellent test-retest reliability among diverse cultures in the US. Three questions of WU-RBA-W used for the present analysis were: do you think your current partner has ever cheated on you, have you ever cheated on one of your partners and which statement best describes your chance of getting HIV. The first two questions have a dichotomous response option, yes or no. The third question has five response options, from no chance to a sure chance. Women who indicated "no chance", "small chance" or "50/50 chance" were considered low risk, and those who indicated a "strong chance" or "sure chance" were considered high risk.

Exposure to violence was assessed with the Violence Exposure Questionnaire (VEQ), a self developed instrument. Women were asked, "In the past 12 months, has anyone (a) abused you emotionally, that is, did or said things to make you feel very bad about yourself or your life (b) pressured or forced you to participate in sexual acts against your will (c) hurt you to the point that you had bruises, cuts, broken bones or otherwise physically abused you (d) attacked you with a gun, knife, stick, bottle or other weapon". These questions have a dichotomous response option; yes or no. A positive response on any of these four statements indicated presence of violence.

Both the RBA and VEQ were modified and contextualized to suit the Indian culture. The assessments were translated and back translated using the standard procedure for translation, to ensure content validity (WHO, 2003).

Analysis

The sample was stratified into two groups, women who consented for HIV testing (42%) and women who refused consent for HIV testing (58%). Descriptive statistics, bivariate and multivariate analyses were conducted using SAS version 9.1.

RESULTS

Demographics

Women were an average 30 years of age (SD=6.46). Twenty seven percent of the sample was illiterate, 12%, 37% and 24% received primary (1-4 years), middle (5-7 years) and high school (8-10 years) education respectively. Over one third (37%) of the sample was employed either full time or part time. The annual income of two thirds of the sample ranged from Rs. 2000 to 6000 (approximately USD \$53 to \$158). A majority (93%) of women was residing in rented Government Housing and nearly all (99%) reported a monogamous marriage.

Risk perception and Exposure to violence

Women who consented and refused HIV testing were compared on risk perception in self and/or spouse, perceived risk of contracting HIV infection and exposure to violence. No significant differences were found between groups on risk perception in self and spouse, perceived risk of contracting HIV infection or exposure to violence. Only one woman reported to have cheated on her partner. Twenty three women reported that their husband had cheated on them. Six women (3 in each group) reported to be at high risk of contracting HIV infection. A significant proportion of women (N=45) reported being exposed to at least one form of violence in the last 12 months, though these behaviors did not significantly differentiate women who consented to HIV testing from women who refused to test (Table 1).

Reasons for Refusal

Reasons that predominantly contributed to refusal to test for HIV are shown in Table 2. Three were most common: believing that they were not at risk or would be negative (29%), fear of negotiating with spouse or spouse denying permission to test (28%) or fear of negotiating with family or family denying permission to test (12%, or 40% combined), and having already undergone testing during pregnancy (21%). Few women were afraid of a needle prick (2%), feared the outcome of testing (2%) or believed that they were too old to contract the virus (2%).

Reasons for Consent

Reasons that predominantly motivated women to consent for HIV testing are shown in Table 3. The most common reasons were: easy accessibility of the testing site (79%), free testing (69%), and understanding the importance of testing (69%). All the 42 women who consented for HIV testing were negative for HIV.

A multiple logistic regression was computed to determine predictors of consent. Younger age, higher education, exposure to violence, perceived high risk behavior in spouse and high risk of contracting HIV did not predict consent to HIV testing significantly.

DISCUSSION

Efforts are being made to increase the uptake of HIV testing in the community. However, very few studies have systematically explored possible reasons for refusal and consent in specific populations. The participants of the present study were wives of heavy drinking men. Hence, high risk behavior in spouse and self, and exposure to violence were considered salient variables likely to influence consent rates. In addition, the influence of socio-cultural or contextual factors was also studied.

The findings indicate that less than half (42%) the women in our sample consented for HIV testing. Women, who consented to versus those who refused HIV testing, did not differ significantly on socio demographic and risk behavior variables. However, the above finding needs to be replicated in larger samples as very few women in the present sample reported high-risk behavior in self (N=1) and high chances of contracting HIV infection (N=6). Further, only the woman's report of risk (in self, in spouse and risk of contracting HIV infection) was assessed in this study.

Risk perceptions were found to be low despite husbands' problem drinking. This may be explained by the oft-cited disparity between real and perceived/personalized risk and, a lack of awareness about the relationship between heavy drinking and high risk behavior. Although a large number of women (45%) reported a recent exposure to violence, significant group differences did not emerge. This finding has important implications for women who consent to HIV testing against their husband or other family member's will.

Stigma associated with HIV/AIDS was a universal concern endorsed by most women in the present study, a finding corroborated by studies from the West (Speilberg et al, 2003; Zhang et al, 2007). Stigma in the present study was not assessed using a structured measure but instead was inferred from the qualitative data obtained through field notes maintained by the research staff. Perceptions of stigma seemed to be generic, that is, women felt that the condition of HIV/AIDS was associated with stigma. They, however, did not feel stigmatized about participating in an HIV prevention study or accessing HIV testing services at the PHC.

A combination of social, logistic and awareness related factors seemed to influence consent to HIV testing in the community. Social factors were: consent of family, collective decision-making and empowerment of women. While 40% of the women refused consent because the spouse or family (mother-in-law in most cases) prevented them from being tested, 38% reported that one of the reasons for consenting was because their family permitted them to do so. Logistic factors, such as free and easily accessible counseling and testing service played a major role in consenting to test, as has been found in studies from developing countries (Kawichai et al, 2007; Thielman et al, 2006). Awareness was also a major reason for testing; while 29% of the women refused consent because they believed they were invincible, 31% consented because they believed they were at risk.

In a collectivistic culture such as in India, decision-making occurs subsequent to negotiations and discussions with significant others in the family (Triandis, 2001; Wu & Keyser, 2007). This is particularly so among married women with lower levels of education, who are unemployed and in socio-economically disadvantaged sections of the society. Although, nearly one third of the women who consented, did so because their family permitted them to get tested, nearly half the women feared offending their spouse and family, and did not feel empowered to make a decision independently. Thus, consent of family and collective decision-making influences consent rates. Rather than discouraging women from discussing these issues with spouse/family, interventions must include the rationale for testing and the benefits of testing to self and family. Conviction about the importance of HIV testing and a realistic risk appraisal, will lead to higher consent rates (Jones et al, 1993; Killewo et al, 1998; Zhang et al, 2007).

Interventions ought to teach women to improve their negotiation skills through role plays and help them communicate better with spouse and family. Programs that encourage the involvement of the spouse and family are likely to be received with greater acceptance in some cultures (Bond et al, 2005; Taegtmeier et al, 2006). The present study has also tapped myths and misconceptions such as beliefs that one is not at risk, that one is too old to contract HIV and that repeat testing is not required. Educational programs therefore, ought to create awareness, demystify HIV/AIDS and, highlight the need for retest in the context of one's continuing risk for HIV.

Women recruited for the present study were younger, less educated, mostly unemployed and in a monogamous marriage. HIV preventive interventions focusing on married women in a younger age group are important for two reasons: one, these women are likely to be more sexually active and hence, their chances of contracting HIV infection are high and two, women are more likely to be receptive to interventions (Ole King' Ori, 1994) compared to men. In addition, women from socio-economically disadvantaged settings, with lower levels of education, who are unemployed, tend to be less informed about health related issues, and as a result, are less likely to access VCT services. Hence, provider initiated services in the community become important and relevant.

In an effort to increase the uptake of HIV testing, provider initiated testing and counseling services and the 'opt out' policy in HIV testing have been emphasized (CDC, 2006; WHO, 2007). The finding that obtaining a separate and specific consent for HIV testing yields lower consent rates is debatable. Refusal of HIV testing may be a consequence of a complex set of factors rather than the consent form alone. While the above policies offer promise in the field of HIV prevention, providers must be aware of and sensitive to other factors influencing consent. Better consent rates among women in developing countries are ultimately achievable by improving logistics, increasing awareness and involving significant others.

CONCLUSION

A combination of social, logistic and awareness related factors influence consent to HIV testing. The findings emphasize the cultural relevance of HIV testing in a community health centre. Since family support was cited as a common reason for consenting and refusing HIV testing, VCT services in India should empower women to negotiate better with their family, and couple rather than individual based HIV counseling may be practiced. A realistic appraisal of one's risk of contracting HIV and the importance of retest may also be emphasized in counseling. Testing policies and practices for low-income monogamous women in India need to be developed.

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Table 1

Comparison of women who consented vs. refused on risk perception and exposure to violence

Variables		Consented (N=42)	Refused (N=58)	χ^2
		Frequency (%)	Frequency (%)	
Have you ever cheated on one of your partners?	Yes	01 (2%)	00 (0%)	
	No	41 (98%)	58 (100%)	
Has your current partner ever cheated on you?	Yes	11 (26%)	12 (21%)	0.81
	No	31 (74%)	46 (79%)	NS
Which statement best describes your chance of getting HIV?	High	03 (07%)	03 (05%)	0.68
	Low	39 (93%)	55 (95%)	NS
In the past 12 months has anyone abused you Emotionally, Sexually Physically or Attacked you with a Weapon?	Yes	20 (48%)	25 (43%)	1.07
	No	22 (52%)	33 (57%)	NS

• Chi Square test and Fisher's Probability test could not be computed as cell value was <5 and 0 respectively; NS=Not Significant

Table 2

Reasons for refusing consent for HIV testing (N=58)

Sl. No	Reasons	Percentage
1	Believed that they were not at risk or would be negative	29%
2	Fear of negotiating with spouse or spouse did not give permission for HIV testing	28%
3	Underwent HIV testing during an earlier pregnancy	21%
4	Fear of negotiating with family or family did not give permission for HIV testing	12%
5	Ran out of time	04%
6	Feared needle prick	02%
7	Feared the possible outcome of testing	02%
8	Felt she was too old to contract HIV infection	02%

Table 3

Reasons for consenting for HIV testing (N=42)

Sl. No	Reasons	Percentage
1	Testing site was easily accessible	79%
2	Testing was offered free of cost	69%
3	Understood the importance of testing	69%
4	Family permitted them to get tested for HIV	38%
5	Women felt that they were at risk for HIV	31%
6	Women agreed because it was part of the protocol	12%
7	Wanted to get it over with	02%