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Addressing prevention among HIV-uninfected women in PMTCT programs in South India

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Abstract

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With nearly one million HIV-infected women in India, prevention of mother-to-child transmission (PMTCT) programs serve an important role. While PMTCT programs focus on mothers living with HIV infection, offering them to uninfected pregnant women may prevent maternal HIV infections. To inform future efforts to offer PMTCT programs to uninfected women, we conducted focus groups with 24 uninfected women in the South Indian state of Karnataka who had given birth within the previous 2 years to explore their perceptions and experiences about HIV education and screening during pregnancy. Although all the participants had undergone HIV testing at a public health facility during pregnancy, they reported little knowledge about HIV transmission or prevention. Revisions are needed in existing PMTCT program curricula and instruction methods before they can be offered to uninfected women as an HIV prevention strategy.

Keywords

health care; HIV prevention; India; prevention of mother-to-child transmission of HIV; women

In 2017, Asia had the second highest number of HIV infections in the world, with 5.1 million individuals living with HIV (United Nations Programme of HIV and AIDS [UNAIDS], 2017). India accounted for more than 2.1 million of those cases, with the highest prevalence recorded in Nagaland, Mizoram, and Manipur in the northeast and Andhra Pradesh and Karnataka in the south (National AIDS Control Organization [NACO], 2017). Women account for 40% of the cases. The primary mode of HIV transmission to women is heterosexual activity and has spread from high-risk populations to the general population. Reports have indicated a staggering 75% of Indian women with HIV infection contracted it within a few years of their marriage (Solomon, Chakraborty, & Yephthomi, 2004).

Pregnancy has, therefore, been identified as a unique opportunity and point of entry to engage women who otherwise have limited access to HIV screening and care. In recent years, the global health community has set goals of increased prevention of mother-to-child transmission of HIV (PMTCT) programs (Figure 1) in a valiant effort to drastically reduce HIV. The National AIDS Control Organization (NACO) in India, recognized the importance of PMTCT programs, and nearly doubled its testing and counseling centers from 2,815 centers in 2005 to 5,135 centers in 2009 (Merchant & Lala, 2005). Much emphasis has been placed on hospital-based screening and prevention programs. For pregnant women diagnosed with HIV, intensive antiretroviral therapy (ART) is available and can lower the likelihood of transmission to the infant from 40%, if untreated, to less than 2% (UNGASS, 2010) (Figure 2).

Prevention of mother-to-child transmission programs have made great strides in keeping mothers and their children. Below, is a broad four-pronged strategy to inform national guidelines for preventing transmission to children and keeping mothers alive, outlined by the UNAIDS (2011, p. 12):

Prong 1: Prevention of HIV among women of reproductive age within services related to reproductive health such as antenatal care, postpartum and postnatal care and other health and HIV service delivery points, including working with community structures.

Prong 2: Providing appropriate counselling and support, and contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births, and to optimize health outcomes for these women and their children.

Prong 3: For pregnant women living with HIV, ensure HIV testing and counselling and access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery and breastfeeding.

Prong 4: HIV care, treatment and support for women, children living with HIV and their families.

Building on these guidelines, the National AIDS Control Organization (NACO, 2013) of India outlined a detailed approach to PMTCT protocols and services to be offered to pregnant women who were diagnosed with HIV as well as instructions for women without an HIV diagnosis. Guidelines for HIV-uninfected women include safe sex counseling, linkages to family planning services, and behavior change communication for high-risk women and partners (NACO, 2013). This study addresses pregnant women who are found to be HIV-uninfected in a PMTCT program.

Based on the NACO Technical Estimates Report (NACO, 2016), approximately 47% of pregnant Indian women accessed some form PMTCT screening or care. Of the 12.7 million pregnant women who were tested, 11,900 were found to be infected with HIV. Many studies have focused on ways to increase the number of pregnant women getting tested (Thompson et al., 2012), barriers to PMTCT programs (Busza et al., 2012), and loss to follow-up (Msellati, 2009). However, little is known about the impact of PMTCT programs on the vast majority of women undergoing education and testing in PMTCT programs. Considering the extensive resources invested in PMTCT and the sheer number of women tested through PMTCT programs, we know very little about the quality of HIV education for women who are found to be uninfected after undergoing pre-test education and counseling in PMTCT programs. It is also unclear whether pregnant women who test HIV negative are in a better position to prevent HIV infection in the future. The goal of our study was to interview HIV-uninfected women who had participated in PMTCT programs to assess their knowledge, comprehension, and/or retention of information provided in these programs. In doing so, we aimed to identify barriers to HIV awareness and prevention within PMTCT programs and ways to improve these programs to have a greater impact.

THEORETICAL FRAMEWORK

The study design and methods were guided by the PEN-3 theoretical model. The PEN-3 model explains the cultural context of health decision-making and has been validated in prior studies of HIV, cancer, and cardiovascular disease (Iwelunmor, Newsome, & Airhihenbuwa, 2014). The PEN-3 posits that there are three interrelated dimensions, namely, cultural identity (CI), relationships and expectations (RE), and cultural empowerment (CE) (Airhihenbuwa, 2007a), with three dimensions in each. In CI, the dimensions are person, family, and neighborhood and their impact on health decisions. In RE the dimensions are perceptions, enablers, and nurturers and the impact their impact on beliefs and resources. In CE the domains are positive, existential (cultural influences), and negative and ways in

which they contribute to health outcomes. The model is implemented in two phases, the assessment phase using the RE and CE domains, followed by the intervention stage using the CI domain. This study focused on the assessment phase only. Using this approach offered a sociocultural framework to uncover general perceptions of health care service and HIV-knowledge. These concepts were further customized during community advisory board meetings and then operationalized in the study discussion guide and PEN-3 themes were used in the thematic analysis of focus group discussions (FGD).

METHODS

SETTING AND SAMPLE

Our study was carried out in the Mysore District of Karnataka, one of four Indian states with the highest HIV prevalence, with approximately 250,000 PLHIV in Karnataka alone (NACO, 2014). The regional language spoken in Mysore is Kannada. As of the 2011 census, the total population of Mysore District was 2,994,744, with 41% living in urban areas. Eligibility requirements for the study included women who (a) received antenatal care and HIV testing in a public health facility, (b) gave birth within the previous 2 years, (c) reported being uninfected with HIV, (d) had the ability to speak Kannada, (f) were at least 18 years of age, (g) were able to provide informed consent, and (h) were willing to be audio-recorded. Recruitment flyers were posted in several central locations, such as health clinics, women's social groups, and community bulletin boards.

In preparation for the study, investigators met with a community advisory board in Mysore, to gain insight into culture-specific factors related to the study question. Additional community gatherings were held to explain the study to the community and their input was incorporated into the final interview guide. To ensure protection of human rights and ethical procedures, the study was reviewed and approved by institutional review boards in the United States, at Florida International University, and in India, at the Public Health Research Institute of India in Mysore. Informed consent was obtained from all participants and every effort was made to meet the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

INTERVIEWS

Four semi-structured focus group discussions (about 75 minutes each) were conducted to enable participants (6 per group) to share information and their experiences in a comfortable and unhurried manner. The group facilitator was a trained research assistant at the Public Health Research Institute of India and spoke fluent Kannada and English. The facilitator had formal training in social work and qualitative methods. Using the PEN-3 model (RE and CE) as a springboard for discussion, the facilitator collected information on demographics, antenatal care, experiences related to HIV testing, and PMTCT. The women were asked to describe their experiences with HIV screening and counseling. The interviews were conducted in Kannada. To ensure proper documentation of the information, each group had a facilitator, a research assistant to take notes, and an audio-recorder. After debriefing, two research assistants on the project transcribed focus group discussions verbatim; the transcripts were then translated into English by an independent translator from the Indian

Institute of Languages to ensure accuracy. The translators were experienced in qualitative research methods and have done similar work in the past. All participants received rupees 150 (USD \$3) as compensation for their travel expense and time.

DATA ANALYSIS

Two researchers, using open coding and a grounded theory approach (Corbin & Strauss, 1990), completed the preliminary coding independently. They then met to discuss common themes and reach agreement regarding the primary themes and to create a codebook based on those themes. Qualitative data analysis software NVivo 10 (QSR, 2012) was used. The coders reviewed coding collaboratively and agreed on the recurrent themes.

RESULTS

A total of 24 HIV-uninfected women participated in four focus group discussions. Their ages ranged from 19 to 32 years (mean = 24) and they had completed an average of 9.2 years of formal education. Seventy-five percent identified as Hindu ($n = 18$), 17% as Muslim ($n = 4$), and 8% ($n = 2$) as Christian. All the women were married and were not formally employed.

Participant knowledge of basic information about HIV and prevention of mother-to-child transmission was limited and, in some cases, entirely deficient. When asked to reflect on their knowledge, few of the participants had a clear idea of HIV prevention or transmission and there was a general sense of ambiguity regarding the screening process and the roles or titles of Integrated Counseling and Testing Center (ICTC) screeners. Four recurrent themes were identified under one or both of the RE and CE Pen-3 domains: HIV knowledge (RE, CE), ambiguity (CE), teaching model (RE), and fear of reproach (RE, CE).

HIV-KNOWLEDGE

When asked about pre-test counseling and if they knew about PMTCT, most respondents were not well informed and some knew nothing about preventing HIV transmission, despite undergoing screening. Participant 1 said, "I do not know how HIV/AIDS is transmitted or how to prevent it."

AMBIGUITY

In some cases, ICTC services were available, but not all women were directed to them and, in many cases, they were not aware of the existence of such facilities. There was also considerable ambiguity regarding the purpose of ICTC services and the roles of health care workers (HCW) providing these services. In some cases, the lab technicians were responsible for providing patients with information about HIV. Even in cases when participants had had pre-test counseling, they were not aware that they were receiving counseling from a trained HCW. The quotes below are from women who went to the same hospital, yet reported different experiences. Participant 3 said, "There was a person sitting at the counter, with information about HIV...I do not know if it was a doctor or nurse but they shared information about HIV and getting tested." And Participant 1 said, "I did not receive ICTC services... I was not directed to their office."

TEACHING MODEL

Pre-test counseling was described by most participants as one-sided communication, using words such as “taught,” “told,” and “educated.” The sessions were usually conducted in a group format and lasted 15 to 20 minutes. When asked about the sessions, one participant described it as follows:

We were taught that HIV comes from a virus that can come from having sex with more than one person, or after injecting an HIV person if the same needle is used, it might transfer the HIV to another person. Then they drew blood for testing.
(Participant 6)

The primary method of HIV education was verbal communication. Other illustrative methods such as flipcharts, posters, and audio/visual media were not employed. In some cases, visual aids were used, but HCW did not take the time to properly explain the material’s content to illiterate patients. Almost all received oral instruction regarding HIV prevention. When asked which method they preferred, participants felt that a combination of oral and visual information would be the most effective to educate people about HIV.

There was a form with general information about HIV and how it spreads. The HCW read from the paper. There were no illustrations. There were some posters on the wall, but I cannot read. I asked the person near me but she also did not understand. (Participant 2)

FEAR OF REPROACH

Despite statements by participants that they did not understand the HIV instruction and that they desired to better understand how to prevent HIV, none opted to join post-test counseling sessions. Some participants assumed that further HIV education/instruction was unnecessary because they were uninfected. Others seemed afraid or uncomfortable asking for information. Participant 1 said “If I do not have HIV, then why would I need to know about it? I was just grateful that I did not have it.” And Participant 3 added, “I wanted to know more, but the people giving the instruction did not have patience and might lose their temper.”

When discussing their overall experiences at the hospitals, some participants described verbal abuse, mistreatment, and discrimination. These experiences may have impacted the ability to inquire about procedures, care, or general information. It also may have disempowered some women, preventing them from taking an active role in their health care decisions. Participants reported that they were afraid of saying something incorrectly or asking the wrong question. They were concerned that their questions would elicit impatience, anger, or mistreatment from the hospital staff. Participant 4 said, “I would have liked to know more, but I worried that the HCW might become upset with me.” And Participant 5 said,

The staff in the hospital shouted at the patients and demanded that we “keep quiet.” Sometimes they hit the patients. If patients are uneducated or cannot read, the staff make decisions for them instead of explaining it to them. They force us to do what they decide.

DISCUSSION

Despite undergoing HIV screening, the majority of participants in our study had little knowledge regarding HIV transmission and its prevention. There was also considerable ambiguity regarding the role of the PMTCT program and where it fit in the hospital hierarchy. Most of the women did not know the role or title of the ICTC counselors, they perceived the teaching model as a brief lecture on basic HIV information, and they did not feel comfortable asking questions or asking the instructor to repeat topics that were not clear. Some women feared reproach or abuse if they inquired beyond what was shared in the instructions.

Participants received virtually no post-test counseling and their general understanding was that an HIV-uninfected status indicated safety from infection and further information or education was unnecessary. This notion was shared, if not implied, by HCW as well (data not presented here). This demonstrated an unfortunate lost opportunity in HIV prevention.

It is important to note that PMTCT programs have been primarily focused on pregnant women living with HIV and they have been successful in curbing mother-to-child transmission of HIV (Figure 2). Improvements are needed to ensure that these programs are also effective for preventing HIV infections among non-pregnant women. Based on our findings, existing PMTCT programs were deficient in the delivery of pre- and post-test counseling and in educating women about HIV screening and prevention. Education content and instruction methods might be tailored to meet the needs of women from diverse culture and education backgrounds. The overall treatment of participants also highlighted potential barriers to women's abilities to absorb and retain information shared in these programs. Looking forward, it would be beneficial to incorporate multi-modal instruction tools, more comprehensive pre-test education for all pregnant women, opportunities for questions and discussion, and perhaps exit surveys to better evaluate program success and inform modifications.

STRENGTHS AND LIMITATIONS

PMTCT programs are an excellent way to reach the 29 million pregnant women in India. Our study was important because it challenges PMTCT programs to broaden their scope and maximize resources by: (a) improving the content and instruction methods of pre-test counseling, as it may be the only instruction women receive; and (b) expanding target populations to include uninfected women, in order to prevent future infections. Our findings suggest that existing PMTCT programs need to update their education, curricular, and instruction models to convey a clearer message about HIV prevention. Limitations include a small sample size, large volumes of data that might be difficult to analyze, as well as the potential for social desirability bias. In addition, because participants were self-selected, the results should be interpreted with some degree of caution.

CONCLUSIONS

It would be beneficial to modify PMTCT programs in India to include a comprehensive and culturally competent method of educational instruction for HIV prevention. This would

include all pregnant women undergoing HIV screening and counseling irrespective of HIV serostatus. This may help to prevent new HIV infections in pregnant women who may not voluntarily enroll in HIV prevention programs.

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Key Considerations

- While recognizing the progress of PMTCT programs in South India there are still inconsistent outcomes in HIV awareness and education.
- These data underscore the need for improved methods of instruction and education in PMTCT programs.
- PMTCT programs must expand their curriculum for greater inclusion of HIV-uninfected women.
- Solely focusing on HIV-infected women undermines a unique opportunity to reach the vast majority of the 29 million pregnant Indian women.
- Future research should focus on healthcare provider's capacity and ability to provide effective instruction on HIV-prevention.

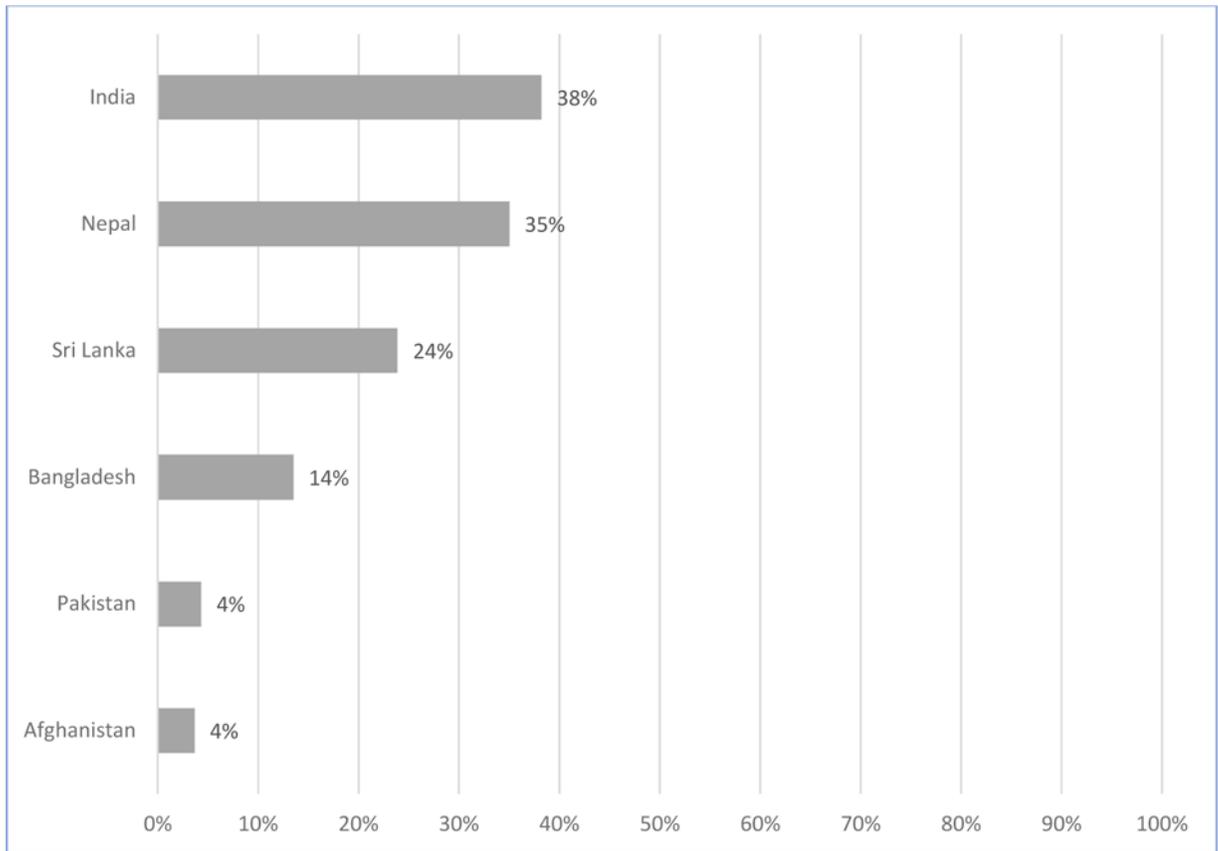


Figure 1. Percentage of pregnant women living with HIV receiving most effective ART for PMTCT, South Asia, 2015.

Note: Bhutan and Maldives not available; ART = antiretroviral therapy; PMTCT = prevention of mother-to-child transmission.

Source: UNAIDS 2016 estimates.

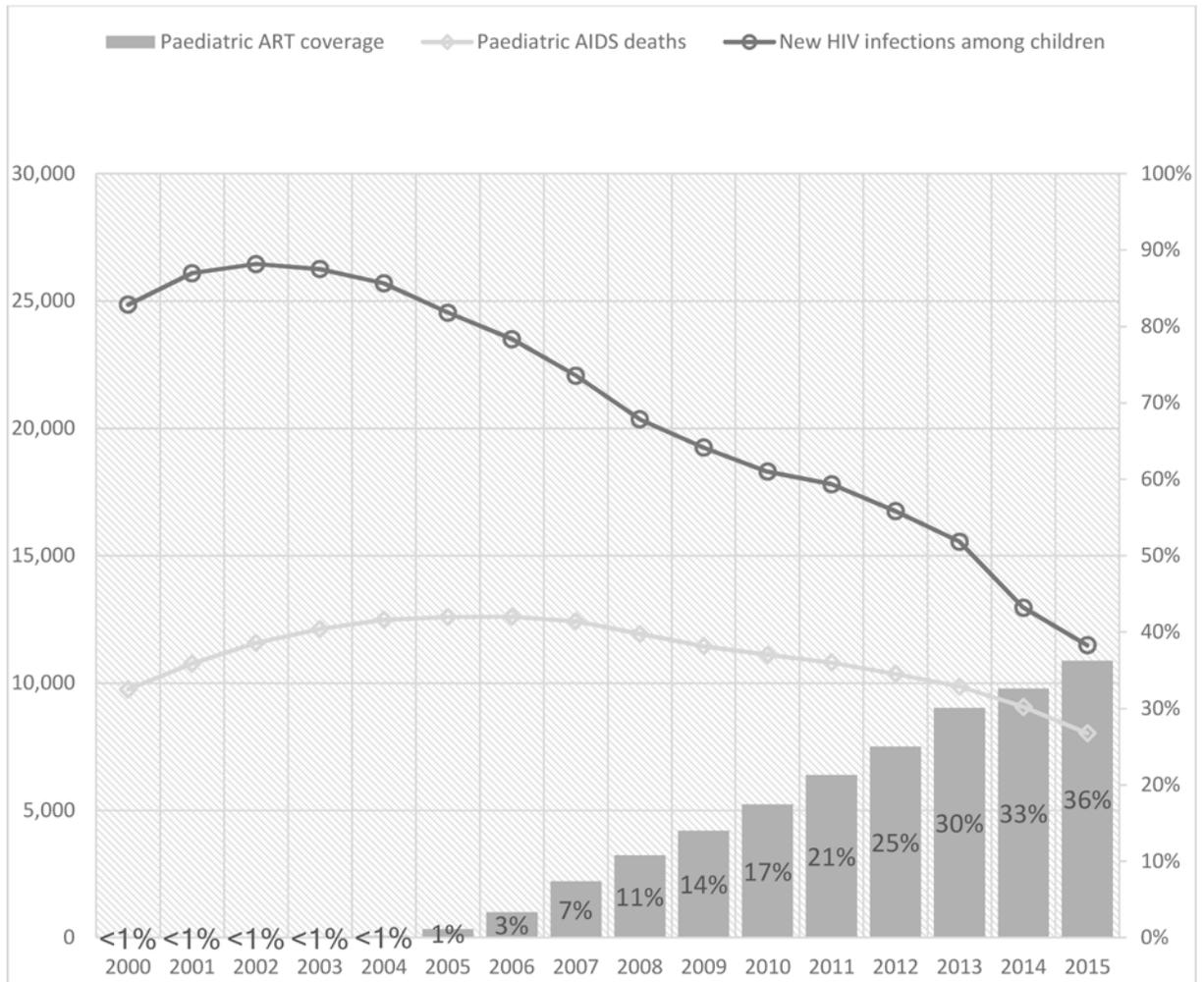


Figure 2. Trends in coverage of ART, number of new infections, and number of AIDS-related deaths among children (ages 0–14), South Asia, 2000–2015.

Note. ART = antiretroviral infection.

Source: UNAIDS/UNICEF/WHO Global AIDS Response Progress Reporting and UNAIDS 2016 estimates.