

VITAL VOICES:

Findings from
consultations with
people living with HIV
on the prevention of
vertical transmission

OBJECTIVES

The aim of this study was to solicit the views of people living with HIV (PLHIV) on barriers and opportunities in relation to the prevention of vertical transmission (PVT), with emphasis on the first two prongs of the global PVT strategy (prevention of HIV among women of reproductive age and prevention of unintended pregnancy among women living with HIV). The study was conducted by the International Community of Women Living with HIV (ICW Global) and the Global Network of People Living with HIV (GNP+).

METHODS

This study used a participatory and mixed method approach. Between November 2010 and January 2011 the study applied the following, different data collection techniques: a qualitative e-consultation (66 PLHIV from 16 countries, focus group discussions (FGDs) with people living with HIV (27 PLHIV from Jamaica); an online e-survey (591 PLHIV and people affected by HIV from 58 countries); and a panel discussion with experts from the field.

FINDINGS

Overall, the consultation revealed both **barriers** to and **facilitators** of access to family planning and other prevention services. These findings highlight a variety of **opportunities** for effective scale-up. The essential package of comprehensive PVT services was reportedly available almost everywhere in the participating countries. However, availability did not equal accessibility. Service providers' attitudes were among the greatest barriers to access (as stated by 70% of the e-survey respondents). There was also little integration between HIV and family planning services: 41% of the participants reported that family planning services were available at HIV clinics, while 74% reported that HIV prevention services were delivered at family planning sites.

BARRIERS

Insufficient knowledge

The qualitative results of the FGDs revealed knowledge gaps among the participants in relation to the services available for preventing vertical transmission. Few participants were able to describe services to prevent unintended pregnancies or transmission. This was largely due to medical staff spending insufficient time with their patients to discuss these available services. Additionally, the implementation of PVT programmes was not uniform across Jamaica (i.e. different guidelines and various models of different quality), and this added to the confusion amongst focus group participants.

Service providers' judgmental attitudes

About one third (31%) of the e-survey's respondents stated that they had been pressurized at least once by health care workers to make a specific decision about their sexual and reproductive health (SRH), such as accept a hysterectomy, tubal ligation, or abortion. Providers had also refused to offer family planning options to women living with HIV or to assist with their deliveries.

A concern often expressed in the e-consultation and FGDs referred to the general advice to simply abstain from sex. Service providers' judgmental attitudes may lead to self-stigmatization, and as a consequence PLHIV giving up on their SRH-related rights - about two thirds (59%) of the e-survey respondents felt that women in their countries were not aware of their SRH-related rights.

"The sector is heavily influenced by biomedical views whose approach is to advise [couples] no, [and] tell discordant couples to have little or no sex at all let alone conception."
(e-survey participant).

"Society on a whole believes that I should stop having sex. My family believes I should stop having sex. My mother told me specifically, don't think about men. And when I sat down with her and explained that I would like to get married...she pretended not to hear."
(female FGD participant, Jamaica).

HIV-related stigma and discrimination

About two thirds (69%) of the e-survey's respondents reported being stigmatised in health care settings, most commonly in HIV clinics, closely followed by primary care and dental care facilities. More than half of respondents (53%) stated that their right to keep their HIV status confidential had been violated in the past, most often by health care providers.

Gender-based violence (GBV)

The results of both e-survey and e-consultation showed that GBV prevented women from accessing voluntary counselling and testing programs, disclosing their HIV status to their partners, and negotiating safer sex with their partners, all of which reduced women's control over their own fertility. Half of the respondents felt that women in their countries were at risk of sexual violence (e-survey).

“Violence is one thing that is so common in my country. Cases are commonly reported in press for men murdering their wives because of disclosing the HIV + results after the testing, women are battered because of introducing the condom after sometime of marriage ..., the continuous rapes and gang rapes, all these atrocities inflicted to young women who in most cases are economically helpless, fuel the MTCT especially among these young women...” (female participant, e-consultation, Uganda).

OPPORTUNITIES

Increasing the quality of counselling

Overall quality of counseling received in relation to prevention services was mostly rated as average, as shown in the table below:

Quality of counselling (as evaluated by the e-survey participants)	Excellent -Good	Average	Poor-Very Poor
HIV test offered at family planning, STI or antenatal services	32%	40%	28%
Prevention of pregnancy	43%	41%	16%
Services to conceive safely	55%	24%	21%

Service providers' judgmental attitude was identified as the main factor for low quality of counselling. Also the FGD's findings pointed to a gap in counseling: “Generally, counseling is not done and indications are that an increasing number of women [living with HIV] are having unplanned pregnancies.” In addition, qualitative data (e-consultation) showed the need for appropriate timing, careful selection of testing venues, and culturally appropriate counseling when expanding voluntary counseling and testing services (VCT). The need for complementary peer-counseling was also highlighted. Experts participating in the panel discussion stressed the need for safeguarding patients' rights and confidentiality with provider-initiated testing and counseling (PITC) during antenatal care. Participants also felt that providers should receive adequate training to implement a rights-based approach to care.

Promoting male involvement

A coherent finding across the different data sources was the need to promote male involvement in prevention services. Participants reported a gap in the provision of couples counseling and peer-support for men living with HIV or men in sero-discordant relationships with women living with HIV. Fostering male involvement and understanding of HIV and reproductive health was also seen as paramount to supporting safe disclosure of one's status to a partner.

Safe disclosure is the first step for male involvement in preventing vertical transmission and participants felt that 1) women need to be supported to gauge whether and how to disclose their status and that 2) providers need to understand the role that violence and stigma may play in a woman's decision not to disclose.

The quantitative results corroborated this finding. Fifty one percent (51%) of the e-survey respondents felt that men were not encouraged to consult family planning services, and only 28% of respondents could name such services in their respective countries. Respondents thought that this was because family planning was still regarded as a 'woman's domain'. In addition, 63% of survey respondents found that lack of programs targeting HIV discordant couples was a barrier to male involvement.

“Men can't just get up and go want information. The woman has to let him from the beginning...” (male FGD participant, Jamaica).

Community participation and decentralization of services

Participants in each of the four consultations stated that peer support was key to the quality of the continuum of services, starting from testing and counselling services to beneficial outcomes for mothers living with HIV when linked with trained peer mothers. The practical problems encountered in accessing services (as documented by the e-survey: professional service providers' attitudes, financial and transportation problems, long waiting hours) called for a decentralization of services.

Findings from the e-consultation pointed out that many women in resource constrained settings delivered at home with assistance from a traditional birth attendant. Reasons cited included poverty,

judgmental attitudes of health providers, and cultural practices. This highlights the need to explore and optimize community settings to ensure appropriate delivery of prevention in the framework of PMTCT services.

“40% of women have children in hospitals yet few programs collaborate with traditional birth attendants mission homes and local midwives to provide HIV testing services” (female participant, e-consultation, Nigeria).

CONCLUSIONS

Three underlying principles cut across the more specific recommendations for up-scaling of prevention services within a framework of PVT:

- » **The importance of the GIPA principle.** PLHIV and their partners must be meaningfully involved in all aspects of policies and programmes that impact them (UNAIDS, 2006).
- » **The importance of reducing stigma and discrimination.** Protective laws that ensure non-discrimination, reduce stigma, and provide access to justice must continuously address the underlying causes of primary HIV infection and unintended pregnancies. A protective environment creates the conditions for PLHIV to make informed choices about their SRHR (GNP+ et al., 2009).
- » **The importance of addressing SRH-rights and gender issues.** The consultations point to the need to emphasize GBV more strongly. The threat of violence is a barrier to successful PVT on several levels (i.e. HIV disclosure, VCT and family planning). Clear links between gender-based violence and poorer health outcomes for both mother and child as a result of physical and mental trauma have been documented (Heise et al. 2002; Garcia-Moreno et al., 2000).

SPECIFIC RECOMMENDATIONS

Governments and other implementers should ensure a better integration between HIV and SRH services. This is in line with recent research on beneficial outcomes of linkages between the two sectors (Brickley et al., 2011; WHO et al., 2009)

- » Service providers should also consistently be trained on delivering services with an unbiased attitude, respecting the rights of individuals living with HIV, including the right to decide whether or not to have a child, and to proactively foster a culture of mutual tolerance. Using responsible and non-discriminatory language should be part of all trainings.
- » Through support group meetings and peer-to-peer support, organisations of PLHIV play a crucial role in empowering women and couples to know their SRH-rights, to decide freely on their sexuality and take informed decisions on their SRH, and to seek redress when these rights are violated.
- » In addition, PVT-related prevention programs should improve by adding specific components that address areas of unmet need, as identified through this study: preconception counselling, including provision of information and counselling on safe conception, and provision of safe contraceptives for women and couples living with HIV, programs that promote male involvement, safeguarding individual rights when testing for HIV, and peer support for post-test counselling and various aspects of PVT programming.

Published December 2011

For more Information, please contact:
Global Network of People Living with HIV
www.gnplplus.net
and
International Community of Women Living with HIV
www.icw.org