

Commentary

Community voices: barriers and opportunities for programmes to successfully prevent vertical transmission of HIV identified through consultations among people living with HIV

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Abstract

Introduction: In 2010, two global networks of people living with HIV, the International Community of Women Living with HIV (ICW Global) and the Global Network of People living with HIV (GNP+) were invited to review a draft strategic framework for the global scale up of prevention of vertical transmission (PVT) through the primary prevention of HIV and the prevention of unintended pregnancies among women living with HIV. In order to ensure recommendations were based on expressed needs of people living with HIV, GNP+ and ICW Global undertook a consultation amongst people living with HIV which highlighted both facilitators and barriers to prevention services. This commentary summarizes the results of that consultation.

Discussion: The consultation was comprised of an online consultation (moderated chat-forum with 36 participants from 16 countries), an anonymous online e-survey (601 respondents from 58 countries), and focus-group discussions with people living with HIV in Jamaica (27 participants). The consultation highlighted the discrepancies across regions with respect to access to essential packages of PVT services. However, the consultation participants also identified common barriers to access, including a lack of trustworthy sources of information, service providers' attitudes, and gender-based violence. In addition, participant responses revealed common facilitators of access, including quality counselling on reproductive choices, male involvement, and decentralized services.

Conclusions: The consultation provided some understanding and insight into the participants' experiences with and recommendations for PVT strategies. Participants agreed that successful, comprehensive PVT programming require greater efforts to both prevent primary HIV infection among young women and girls and, in particular, targeted efforts to ensure that women living with HIV and their partners are supported to avoid unintended pregnancies and to have safe, healthy pregnancies instead. In addition to providing the insights into prevention services discussed above, the consultation served as a valuable example of the meaningful involvement of people living with HIV in programming and implementation to ensure that programs are tailored to individuals' needs and to circumvent rights abuses within those settings.

Keywords: women living with HIV; people living with HIV; primary prevention; unintended pregnancies; sexual and reproductive health and rights; prevention of vertical transmission.

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Introduction

In 2003, the United Nations adopted a comprehensive approach to the prevention vertical transmission (PVT) of HIV among infants and young children, consisting of the following four essential elements [1]:

1. Primary prevention of HIV infection among women of childbearing age;
2. Preventing unintended pregnancies among women living with HIV;
3. Preventing HIV transmission from a woman living with HIV to her infant;

4. Providing appropriate treatment, care and support to mothers living with HIV and their children and families.

To strengthen recognition, commitment, and programming support on a global scale for the first two elements of comprehensive PVT, the Interagency Task Team (IATT) for Prevention and Treatment of HIV Infection in Pregnant Women, Mothers, and their Children (a coalition of organizations engaged in global PVT work, convened by the United Nations) developed a *Draft Strategic Framework (2010–2015) for Primary Prevention of HIV and the Prevention of*

Unintended Pregnancies in Women Living with HIV in the Context of PMTCT (Draft Strategic Framework). Two global networks of people living with HIV, the International Community of Women Living with HIV (ICW Global) and the Global Network of People living with HIV (GNP+) were invited to review the Draft Strategic Framework and provide recommendations for its strengthening.

To ensure recommendations to the Strategic Framework were based on expressed needs of people living with HIV, GNP+ and ICW Global undertook a consultation funded by UNFPA. This commentary summarizes the outcome of the consultation and presents the views and experiences of people living with HIV on barriers and opportunities in relation to the prevention of vertical HIV transmission with a special emphasis on the first two components of the global PVT strategy, that is, primary HIV prevention and prevention of unintended pregnancies.

Discussion

The consultation was comprised of an online consultation (moderated chat-forum with 36 participants from 16 countries), an anonymous online e-survey (601 respondents from 58 countries), and focus-group discussions with people living with HIV in Jamaica (27 participants).

Online technologies were chosen because they have the advantage of collecting anonymous input globally in a relatively short period of time. They also offer the advantage of targeting difficult-to-reach populations, for example, due to the persisting stigma related to HIV [2].

The consultation highlighted the discrepancies across regions with respect to access to essential packages of PVT services. However, the consultation participants identified common barriers to access, including a lack of trustworthy sources of information, service providers' attitudes, and gender-based violence. The responses also revealed common facilitators of access, including quality counselling on reproductive choices, male involvement, and decentralized services.

For successful primary prevention efforts, participants repeatedly emphasized the need for supportive HIV testing and counselling, particularly in antenatal care (ANC) settings. For the prevention of unintended pregnancies among women living with HIV, participants felt programming should focus on the provision of an "integrated package of service", quality counselling and support for conception.

Barriers to accessing prevention of vertical transmission programmes

The majority of e-survey participants reported that an essential package of prevention services was available in their countries: voluntary HIV counselling and testing, information on family planning options and maternal health, provision of condoms and other contraceptives, and treatment and care for sexually transmitted infections. However, there was clear variation by region and challenges in accessing services despite availability. From the perspective of participants, the reasons for the difference in availability included: uneven geographical distribution of services within countries (service concentration in urban areas and under-coverage in rural areas), socio-cultural factors, and the

absence of a supportive legal and policy environment. In addition, participants consistently noted that users of existing programmes were challenged in accessing services due to cost issues and travel time to facilities.

The Jamaican focus group discussions revealed substantial knowledge gaps, even though at least two-thirds of the women had participated in a prevention programme at some point. Many were not familiar with how programmes were actually rolled-out, and few were able to describe correctly modes of vertical HIV transmission or how prevention of such transmission occurs. This was largely attributed to healthcare workers spending insufficient time to educate their clients. Participants described PVT programmes that followed different guidelines and used different models, which resulted in variations in quality as well as confusion amongst PVT programme recipients of what was prescribed practice according to adopted guidelines. Participants reported that sexuality and contraceptive options were not discussed on a routine basis. Consequently women felt rarely able to make informed decisions about their sex lives, with respect to primary prevention and prevention of unwanted pregnancy. Additionally, some women reported that they were dissuaded from even the consideration of having children and some were forcibly sterilized.

In the e-consultation, perceptions that participants and peer women living with HIV had insufficient PVT knowledge were partly attributed to conflicting messages delivered by service providers, for instance, regarding advice on breastfeeding. Participants felt that information from internet sources and second-hand knowledge of HIV and reproductive health often led to misinformation within communities. The participants emphasized a demand for trustworthy sources of information and stated that clinics, providers, state-sponsored public health messaging, and trained peers are examples of such sources currently available. Providers were generally seen as an important yet under-utilized primary source of information. Participants recommended not only improving oral communications, but producing take-home leaflets in local languages and using simple plain images to allow women to share information with their partners. Support groups were also mentioned as trustworthy sources of information and referral systems, while at the same time providing psychosocial support and ongoing support for health and wellbeing.

Among the e-survey respondents, a striking two-thirds had experienced stigma in the healthcare settings with equal gender distribution. Healthcare workers' attitude towards people living with HIV was identified as the single most important barrier to accessing PVT services. Healthcare worker's negative attitudes were also perceived as threatening safe conception by more than half of respondents, both men and women, who felt that women living with HIV and their partners did not have enough support to conceive safely. In the e-survey, one fifth of participants, men and women, reported that they had been pressured by a healthcare worker to take a sexual and reproductive health (SRH) decision at least once, and around one in eight participants reported that they had been pressured more often. This included calls to abstain from sex, undergo tubal

ligation or hysterectomy, have an abortion, and/or use a condom without access to any other family planning option. One respondent reported having been refused assistance at her delivery. Postings in the e-consultation described situations in which individuals had lost trust in providers and feared to visit services again because of providers' stigmatizing attitudes.

A consistent finding across all consultations related to breaches of confidentiality. Over half of all e-survey respondents reported that their right to keep health information confidential had been violated at least once. Participants in the e-consultation and focus group discussions echoed reports of these violations.

Across all consultations, gender-based violence emerged as a barrier to accessing PVT services. Less than half of the male and female e-survey participants believed that women in their countries could assert the right to be free from sexual pressure or violence. Participants viewed the threat of violence as a barrier to women disclosing their HIV status to partners and women accessing voluntary counselling and testing (VCT) and family planning services. Women fearing violence were also believed to be less able to exert control over their fertility and to negotiate safer sex. In addition, it was recognized that women who knew their status and feared disclosure could not ask for partner support to access HIV-specific prenatal care, they were seen as less likely to adhere to antiretroviral medication, and as more likely to resort to mixed feeding practices to avoid disclosure. Participants from the e-consultation agreed that counselling should avoid inappropriately pressuring a woman to disclose to her partner and that healthcare workers should receive training to be able to recognize the signs of potential violence. Such training should also increase providers' ability to identify the role that violence or the threat of violence plays in women's decision-taking.

Emerging opportunities to improve access to and services for PVT

Participants across the consultations emphasized that peer counsellors and support groups played a vital role in successful PVT and in maximizing outcomes for couples and families living with HIV. Peer support groups and networks of people living with HIV were perceived as safe spaces to discuss SRH experiences and choices. Such spaces were seen as important for individuals to feel connected and valued. About half of the e-survey participants overall were satisfied or extremely satisfied with the quality of the PVT services they had received. However, the perceived quality of counselling differed across services provided: While participants in the e-survey mostly felt that the quality of post-test and family planning counselling was average, the quality of counselling support to conceive safely was rated lower.

We also found differences across regions with respect to overall satisfaction with the quality of counselling, with African participants being generally more satisfied than participants from other regions. This was most pronounced with respect to HIV-test counselling. One explanation for these differences could be that in the African region com-

paratively more community-based organizations provide counselling for HIV-testing.

Qualitative enquiry indicated that participants felt that counselling often was rushed while noting the importance of quality counselling in improving the individual's understanding of their own health and acceptance of their diagnosis. These echo WHO findings that supportive counselling pre- and post-HIV testing increases understanding of HIV, decreases trauma, and increases adherence to medication and awareness [3]. Participants recommended that professional counselling should provide accurate and non-judgmental information and should be complemented with peer one-on-one counselling and group support.

During the e-consultation, participants also stressed the need for careful selection of testing venues and culturally appropriate counselling. Service providers' judgmental attitudes were identified as the main factor for low quality of counselling. Participants stressed that, as newly diagnosed individuals, they had needed time to process the information provided during counselling, which often was not possible because sessions were rushed. Participants also stressed the importance of peer-to-peer counselling by women living with HIV. They recommended that providers should at a minimum be able to link women with peer support groups, and should engage peer counsellors in health facilities wherever feasible. Where health facility staff members were often pressed for time, supportive peers and support groups were described as being able to invest more time and have richer sessions by sharing personal insight and experience, in addition to basic information.

Counselling on family planning and safe conception

Overall, women living with HIV participating in this consultation felt they did not receive sufficient counselling on SRH issues. Their SRH aspirations, sexuality, and contraceptive options were not routinely discussed with service providers. Although many participants in the e-survey reported receiving condoms, the shortage in female condom provision was noted.

The focus group discussions in Jamaica revealed that the lack of counselling around SRH had resulted in unintended pregnancies and women participants reported feeling left alone and unsupported when confronted with an unintended pregnancy. The majority of female focus group participants indicated that the only safe contraceptive option under their control and available to them as women living with HIV was tubal ligation. Among e-survey participants, less than a third had received counselling on safe conception; however, more than half of those who received counselling were extremely satisfied with these services.

Participants' consistent emphasis on the importance of quality counselling to understand their own HIV-positive diagnosis, SRH choices, and PVT echoed a 2010 report from the Kenyan National Network for Empowerment of People Living with HIV. They reported an average of only 15-minute counselling sessions for people living with HIV post-diagnosis, and that much of the PVT specific counselling occurred in groups where participants reported the information was harder to digest [4].

Participants in the various parts of the consultation process pointed to the need for greater involvement of men in PVT. Low male involvement was mainly seen as a consequence of men being discouraged from participating in ANC services.

About two-thirds of the e-survey participants reported that programmes to encourage male involvement in PVT services were available in their countries. Barriers for male involvement were identified in more detail: stigma and discrimination (nearly half of men and women); men's attitude that SRH is a woman's issue, endorsed by more women (just over half) than men (nearly a third); societal or community perception that SRH services are designed for women only (about a third), and traditional and cultural norms (just under a third). An additional third of respondents cited lack of programs for sero-different couples as a barrier to male involvement. Focus group participants from Jamaica emphasized that many men relied on their partners for information about their own SRH, which could lead to misinformation about the risk of HIV transmission to the infant or to a negative partner.

The consultations also revealed a gap in reproductive health services and information available to men living with HIV. Participants agreed that efforts to support women and couples to make informed SRH choices should promote men's active involvement. In particular, the focus group participants felt that there was too little counselling available for men who are in HIV-discordant relationships with women who are living with HIV and their needs should be considered within programming.

When asked for solutions to barriers in accessing services, participants in the e-survey indicated the importance of the decentralization of services, for reasons including lowered transportation costs and less time required for facility visits. However, they pointed out that in decentralized community settings it is even more important to respect the right to keep one's HIV status, or other health-related information, confidential, and that confidentiality had to be ingrained into both the healthcare culture and in the culture of the community. This is relevant in the light of our quantitative finding that more than half of the survey participants had experienced some violation of confidentiality in healthcare settings.

Participants in the consultations were self-selected convenience samples. Therefore, their views do not represent the overall population of people living with HIV. The main purpose of the consultation was to obtain feedback for the PVT strategy. Nonetheless, the consultations covered all regions and revealed consistent experiences.

Conclusions

The consultation provided some understanding and insight into the participants' experiences with and recommendations for PVT strategies. Participants agreed that successful, comprehensive PVT programming require greater efforts to both prevent primary HIV infection among young women and girls and, in particular, targeted efforts to ensure that women living with HIV and their partners are supported to

avoid unintended pregnancies and to have safe, healthy pregnancies instead. Both of these two primary steps in reducing the number of new infections among children require increased SRH education and services for women and girls before they are living with HIV, get pregnant, or both. In addition, several themes emerged consistently amongst participants. Important recommendations given by the participants included, but were not limited to, the need for capacity building and adequate training among service providers to support people living with HIV in asserting their right to sexual and reproductive health, including quality counselling for safe conception and contraception; implementation of supportive services such as VCT and peer-to-peer support; encouraging male involvement in all aspects of services to prevent vertical transmission; greater emphasis on prevention of gender-based violence; and support for disclosure in HIV-discordant relationships. Finally, the consultation serves as a valuable example of the meaningful involvement of people living with HIV in programming and implementation to ensure that programs are tailored to individuals' needs and to circumvent rights abuses within those settings.

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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

GA, GC and CN contributed equally to the manuscript writing, based on an initial draft by the GA. NM was responsible for the e-consultation (moderation, data-analysis, and final report writing). OE was responsible for the FGD research (facilitation, data analysis and report writing). All other authors contributed to revisions of the paper, which was finally approved by all authors.

Abbreviations

ANC, antenatal care; GNP+, Global Network of People living with HIV; ICW Global, International Community of Women Living with HIV; PVT, prevention vertical transmission; SRH, sexual and reproductive health; VCT, voluntary counselling and testing.

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References

1. UNICEF/WHO/Inter-agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children. Guidance on global scale-up of the prevention of mother to child transmission of HIV: towards universal access for women, infants and young children and eliminating HIV and AIDS among children. 2007. accessed 2012 June 21. Available from: http://www.who.int/hiv/pub/mtct/pmtct_scaleup2007/en/index.html

2. Wright KB. Researching internet-based populations: advantages and disadvantages of online surveys, online questionnaires authoring software packages, and web surveys. *J Comput Mediated Commun.* 2005;10(3), article 11. accessed 2012 June 21. Available from: <http://jcmc.indiana.edu/vol10/issue3/wright.html>

3. WHO. Reproductive choices and family planning for people living with HIV: counselling tool. 2007. accessed 2012 June 21. Available from: [\[www.who.int/reproductivehealth/publications/family_planning/9241595132/en/index.html\]\(http://www.who.int/reproductivehealth/publications/family_planning/9241595132/en/index.html\)](http://</p></div><div data-bbox=)

4. NEPHAK. Advancing the sexual and reproductive health and human rights of people living with HIV: the uptake of PMTCT by people living with HIV in Kenya. 2010 Jan. accessed 2012 June 21. Available from: http://www.gnpplus.net/images/stories/SRHR/20100920_SRHR_Kenya_ONLINE.pdf