

ICWGlobal



International Community of
Women Living With HIV/AIDS



Vital Voices

Learning from the experiences and perspectives of
people living with HIV to inform PMTCT
programmes and health facilities/services

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Geneva, 10 May 2011

Background

- Increasing recognition of the expertise of PLHIV in informing normative guidelines
- ICW Global and GNP+ conducted consultations with PLHIV
- Generated recommendations on the IATT Draft Strategic Framework on Primary Prevention and Prevention of Unintended Pregnancies
- Findings on experiences and perspectives of PLHIV in accessing PMTCT and related services

Methods

Combined qualitative and quantitative approaches:

- moderated online consultation (66 participants from 16 countries);
- three facilitated focus group discussions (27 men and women living with HIV in Jamaica);
- an e-survey for people living with and affected by HIV (591 respondents from 58 countries);
- an expert panel to discuss the content and accessibility of the framework (22 participants);

Findings

- HIV-related stigma
- Human rights violations
- Coercion from health providers
- Gender-based violence
- Supportive testing and counselling
- Safe conception and healthy pregnancies
- Couples testing and counselling
- Male involvement

Experience of HIV-related stigma

- 70% of survey participants identified healthcare worker attitude as a barrier and a reason they had not accessed available services
- 69% of survey participants had experienced stigma in the health care setting
- 58% of survey participants felt couples living with HIV did not have enough support to conceive safely, with stigma identified as the major cause

Health Provider Initiated Pressure

- 19% of survey participants had been coerced to make a decision about their sexual and reproductive health by a health care provider once and 12% had been pressured more than once
- The most common pressures were related to preventing or terminating a pregnancy.

A Voice from Uganda

Then when it was time to give birth, the doctor told me that one I was to be operated, I shouldn't have the labor pains, then two that I was supposed to stop on that baby. And I tell you I was sterilized, because I didn't have the choice and I wasn't made to sign anywhere. I just found myself like that. And recently I had to go for a scan, that was when I found out I was sterilized. I was sterilized on October 23, 2005. I found out last year - 2010.” – female interviewee from Uganda

ICW Global, Interviews of members on SRHR, part of advocacy training programme, March 2011

Gender Based Violence (GBV)

Consultation and survey results show that GBV threatens successful prevention of vertical transmission programs because:

- Fear of violence prevents women
 - disclosing their status to partners
 - accessing voluntary testing and counseling and family planning;
 - exerting control over their fertility, negotiating safe sex or condom use, or confronting marital infidelity, all of which inhibit primary prevention efforts.
- There are also clear links between GBV and poorer health outcomes for both mother and child as a result of physical and mental trauma.

Supportive Testing and Counseling

- 49% of e-survey respondents rated overall quality of counseling that HIV-positive women receive as average.
- 19% rated the quality of counseling as poor and 9% as very poor.

A voice from Southern Sudan

“To be counseled by someone who is living with HIV, it is very good because he or she knows the pain. And, she will know how to handle you, and which type of words she should use and which type of words she should not use with you. She will not neglect you because if she feels like neglecting you, she will be neglecting herself as well...” – **female interviewee from Southern Sudan**

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Support for Safe Conception and Healthy Pregnancies

- 58% of e-survey respondents felt that HIV-positive women and couples do not have enough support to conceive safely
- Health workers' judgmental attitudes highlighted as major issue affecting safe conception

Couples Testing and Counseling

“The day I was tested, I was with my husband and we became HIV discordant. I was positive and he was negative. When we were told, to be given back the results, it was as if the health care worker did not have enough time for us. She was like, do you know what discordancy is? I said yeah, then they tell the husband, because he didn’t know. And she said you are negative, you are positive. May I have another couple? They didn’t give us enough time, which resulted the husband to leave me at the health facility, abandon me there, up to now. So I had to give birth minus him.” – female interviewee from Uganda

ICW Global, Interviews of members on SRHR, part of advocacy training programme, March 2011

Male Involvement

E-survey participants identified the following barriers to male involvement in prevention of vertical transmission:

- stigma and discrimination (84%);
- men's attitude that it is a woman's issue (77%);
- societal or community perception that the services are for women only (74%);
- traditional and cultural norms (72%); and
- lack of programs for sero-different couples as a barrier to male involvement (63%).

Action research!!!

Participating in the consultations

→ resulting in demand of rights!

“[one of the participants in the consultation] said she wanted me to know she got home safely and how grateful she was to get the information ... on her rights. Now she could take it to the clinic which had delayed delivering [her] baby because she refuse[d] to sign permission for tying her tube when they deliver the baby. She said that they explained she did not have sufficient amniotic fluid and should operate two weeks ago when the baby was 7 months [along]. It was put off when she refused to sign the permission. She said she sought the support of the social worker and was told she must follow the Doctor’s order. I will be referring her to a counselor today and see how much support we can get for her to have all the information she needs to make the choice that will ensure both her and the baby's health.” – focus group facilitator, in an email to the consultation coordinators, sent from Jamaica on Monday, January 17, 2011 8:34 AM.

What facilitates access to services

- decentralization of services had made them more accessible;
- advocacy, monitoring, and evaluation efforts had removed barriers;
- and personal knowledge and access to information allowed individuals to demand or find the services needed.

Summary of Recommendations

- Education of health care providers on how to provide non-judgmental support to PLHIV accessing PMTCT services;
- Provision of accurate information to PLHIV and their partners and recognition of individual right to test for HIV;
- Peer support as part of post-test counseling and PMTCT programming;
- Support for safe conception and healthy pregnancies;
- Continued consultation and operations research with people living with HIV to ensure policies and programmes are responsive to the needs and experiences of people living with HIV.

Acknowledgements

Support from UNFPA

Project implementation team: Ginna Anderson (ICW Global), Georgina Caswell (GNP+), Olive Edwards (JCW+), Beri Hull (ICW Global), Chris Mallouris (GNP+), Nais Mason (Independent Consultant) and Christiana Noestlinger (Institute of Tropical Medicine, Antwerp).

We are particularly grateful to all the people living with HIV who participated in the consultations and gave their time to make their voices heard!