Planning action around the neglected sexual and reproductive rights of women living with HIV

Interactive dialogue session at the Women's Networking Zone of the XVIII International Conference on AIDS

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These notes summarize a discussion that took place during the XVIII International Conference on AIDS on 21 July 2010. The participants (about 25 in total) came from diverse regions, organizations and disciplines/sectors (e.g., researchers, program implementers, policy advocates) and included women living with HIV. Some participants indicated that they would stay in touch with one another regarding these issues, for example for:

- Continuing debates on how best to plan actions and what kinds of considerations to take into account
- Sharing plans for research, advocacy, programs and interventions and asking others for their input and ideas regarding the plans
- Exploring ideas for collaboration (e.g., on specific studies, co-authored publications, etc.).

Rationale for the session

Maria described the facilitators' motivation for organizing this session:

Despite much rhetoric to the contrary, women living with HIV continue to be approached by AIDS programs as potential vectors of possible transmission of HIV (sexual, vertical). Much of the information and resources channeled to positive women continues to have as a primary concern the prevention of perinatal transmission. In addition to reinforcing societal stereotypes and norms that emphasize a woman's primary task is to reproduce and care for a family, this prevents women from exercising their sexual and reproductive health and rights and can lead to multiple manifestations of stigma for women who do not conform to accepted norms - HIV-related stigma; stigma because they choose to have sex, stigma because some might not want to be biological mothers, stigma because they may wish to terminate an unwanted pregnancy etc. Women living with HIV will be unable to enjoy their full human rights if they are unable to exercise self-determination and the right to decide whether to have children or not, and if so when and how many children to have.

To stimulate more innovative thinking in this area and to highlight some of the most neglected issues in the HIV and rights field, the intent of this hour-long session was to focus on two questions:

1. What actions are needed to promote HIV-positive women's rights regarding sexuality, reproduction and motherhood by: community members, NGOs, political and governmental leaders and donors?
2. What actions can be taken to promote HIV-positive women's reproductive rights more generally, including in relation to access to legal adoption and safe abortion care?

Sofia briefly described a conference, organized early in 2010 by the Program on International Health and Human Rights (PIHHR) at the Harvard School of Public Health (HSPH) with primary support from WHO, that examined the ways in which research, policy and programmatic activities could best support and engage with the pregnancy intentions of HIV-positive women. The intention was to identify what was known, as well as research gaps, about desired pregnancy for HIV-positive women; HIV-positive women seeking to prevent pregnancy; safer pregnancy for HIV-positive women; and pregnancy termination for HIV-positive women.

The conference could only include a limited number of participants but we know that many other people are also interested in these issues and we are seeking ways to continue the dialogue with them as well as the conference participants. Both short and longer reports on this conference are available. The long report can be accessed at:
http://www.hsph.harvard.edu/pihhr/files/homepage/news_and_events/pregnancy_intentions_full_report.pdf

Sexuality and sexual/reproductive health (SRH)

The discussion began with a comment that not much is happening regarding women's sexual health, for both HIV-positive and -negative women, at the local level in some countries (e.g., in Kenya). There is little information available on sexuality and pregnancy planning/avoidance, for example, for sero-discordant couples. In other countries, some work has been done. In the United Kingdom, Positive Women carried out a project on antenatal care and is working on issues such as comprehensive and practical/emotional support for children and disclosure to partners.

A participant involved in programming for women receiving antiretroviral therapy (ART) in South Africa gave examples of where women's fertility intentions were not adequately taken into account. Providers may have attitudes discouraging pregnancy, so that any efforts to integrate SRH-ART services would need to include convincing providers to address fertility desires. Another participant from the same country said that this pointed to the need to have health-care workers properly trained on SRH issues and their obligation to observe the human rights of women living with HIV.

A woman who is working with the Mothers 2 Mothers program in South Africa commented that when health-care providers hear a client is living with HIV, they only advise them to use condoms, without informing them about other contraceptive options. She believed that sensitizing women regarding their rights, in particular to information, can help create a demand for services to which providers would then need to respond; other participants agreed, saying that sensitization of health-care workers nevertheless remains a priority.

A woman living with HIV from South Africa commented that an implicit assumption underlying condom promotion is that HIV-positive women have the power to demand condom use. It is widely recognized that a large proportion of women have no decision-making power at all regarding condom use and contraception; to assume that they suddenly have gained that power once they receive a positive HIV diagnosis is absurd.

Abortion

A participant from South Africa remarked that although that country has quite a liberal abortion law, there are still problems with access to abortion care for women living with HIV – as well as for other women. Although abortion care is free in the public health system, a big barrier is posed by health-care providers who do not want to be involved in terminating pregnancies (invoking the principle of conscientious objection).

A question was posed as to whether traditional birth attendants or healers are being involved in provision of safe abortion services to women living with HIV. Maria remarked that a project in Malawi, in which women living with HIV recounted their experiences with unwanted pregnancies and abortion, showed that traditional healers are particularly involved in clandestine and unsafe abortions. Jeni related that traditional healers in Namibia say that they are asked by women to provide care after they have self-induced an abortion; however, since abortion in that country is widely believed to be illegal, these traditional practitioners would not be expected to reveal that they are providing clandestine abortions.

A woman living with HIV from South Africa remarked that abortion is still heavily stigmatized there, so many women living with HIV will still obtain backstreet abortions, provided, for example, by nurses outside the health sector, because they hope then to avoid some of the stigma. In addition, these providers are always available [no waiting times], even though they do charge for the service. Her advice was that we should recognize their role as community-based providers and not ignore their existence – in particular work to ensure that they have the information necessary to provide safe services.

What evidence is needed to persuade policy-makers to address these issues?

A discussion subsequently ensued about what kinds of information we need to persuade policy-makers to address these issues; what kind of language would speak to them persuasively?

It was noted that there are different kinds of evidence: peer-reviewed articles and studies, anecdotal evidence and that the appropriateness of evidence may depend on the setting where it is to be disseminated. Jeni emphasized the need to have data for policy-makers, who will refuse to take action unless they can point to research. Maria noted that in some countries, Health Ministries have (been persuaded to) collaborated with WHO on carrying out strategic assessments of the situation regarding women's and men's access to contraceptive services/family planning and abortion. Such assessments can provide information useful from a public health point of view. Sofia added that her program has worked with WHO to develop a tool to address laws, policies, regulations and standards of care impacting on SRH, which can also be used as an accompanying tool for the strategic assessments; this tool should be available for use from the WHO website via the Internet soon. She also noted that when we are dealing with sensitive issues, policy-makers may require a higher standard of evidence than would be the case for less controversial issues and this is something that must be addressed.

Another participant remarked on the importance of knowing your audience; different kinds of evidence and arguments will appeal to different groups. For example, one can argue that only promoting condom use is a bad idea from a public health perspective as this approach can lead to more unintended pregnancies and more HIV transmission. The question is: how can we shift the framework – speaking about human rights will not appeal to some policy-makers? We need to frame the issues in language that they can easily incorporate into their existing frameworks, and then move them to recognize the importance of human rights for achieving these outcomes.

A colleague from South Africa commented that this shows that anecdotal evidence is not sufficient. Policy-makers can argue that it is easy to choose anecdotes to illustrate various sides of an issue. We need to do more research; if you cannot do research due to lack of funding/resources, you can try to partner with research institutions who can do it. However, then you must take care to ensure that they share a common set of concerns (or ideology) as a departure point. For example, how do you look at maternal deaths: are they really related to HIV or are they the result of inadequate health-care systems?

Another contribution to the discussion highlighted the need for us to be systematic in our use of concepts, while still using different types of language. For example, the causes of maternal morbidity and mortality don't necessarily need to be framed to policymakers in terms of non-discrimination and the right to health, but we can talk about public health indicators that are related to these rights and raise their awareness through this approach.

A participant from Argentina pointed out that public health data will not necessarily influence policy-makers who have certain political agendas. For example, in South America there is plentiful evidence regarding the causes of maternal morbidity and mortality, but policy-makers still don't want to address issues such as abortion. Researchers there have found it useful to form alliances with feminists and celebrities (such as famous actors) in order to get these issues discussed in public. The context will therefore also co-determine which kinds of evidence and approach must be taken in actions to influence policies. Another woman who has worked against the unnecessary use of caesarean sections in the United States for many years said that many of the same issues discussed here in relation to HIV also apply to that problem. This highlights why it would be useful to collect and disseminate strategies from different regions as we have a lot to learn from one another.