

Making HIV Trials Work for Women and Adolescent Girls
Satellite session
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Creating Meaningful Research for Women: Issues and challenges from the community perspective
Heidi Nass

Thank you very much. I'm very pleased to be part of this panel. It's always a treat to be with good people, especially ones doing great work, on a subject that means a lot to me. Plus, I have to say, I've really appreciated presentations at this conference from panels with community members on them because they speak my language, so I'm glad I get to be that person here.

This is my first international AIDS conference and there's something I've noticed. I see here two buildings...and two languages.

I was at a session in this building on Sunday in which a panelist, a policy person with an international NGO that focuses on women's issues, declared that "gender and sexuality are no longer marginalized." At the very same time, had I been in the other building, the Global Village, I would've heard women, transgendered people, sex workers and certainly gay men decrying the lack of authentic inclusion of their experiences and identities in the strategies and policies designed to address this epidemic.

So...I wish to speak tonight in the language of my life about the things I have learned. Before I do that, I need to acknowledge that I am one person with one point of view. Among other things, I am a white American. Inherent in that is profound privilege, which I must acknowledge.

I will say, though, that all those things I do that were mentioned in my introduction are things I completely believe women all over the world – women who have far less privilege - can do. I have met some of these women, so I know they are there. I'm sure they are everywhere and must be found and encouraged and welcomed. We, all of us, need them.

It does cause tension in me, this notion that I can somehow present "the community perspective." Yesterday I was at a session presented by HIV-positive leaders. Among them was Frika Chia from Indonesia and the Asia Pacific Network of People living with HIV/AIDS (APN+).

Frika talked about this tension, too. Then she said, "If I am a leader, I am a bridger." She spoke of the obligation those of us presenting the issues of our communities have to be conduits. It is upon us to carry forth in both directions and bring closer together the people making policy for our communities, and our communities. It is a humbling assignment, to be sure.

Yesterday was the international women's march - Todas las mujeres, todos los derechos. In addition to "All women, all rights," the cry was for "nothing for us without us." To me, this is not just a chant at a rally – it is the only way forward, including in research, and particularly when it comes to women.

This has not been our history. That much is clear. You are in this room on this evening for this presentation – I know you already know this and there is little about this truth that is not obvious.

If we all really do share the goals of: thoroughly understanding women's bodies and the strengths and vulnerabilities of women's lives; improving the lives of positive women; and determining how best to protect our future, young women and adolescent girls, from HIV - it must be the way forward.

Global policies and population guidelines fill an obvious need worldwide. The thing is, by its very nature, HIV is about the individual and individual relationships. Transmission is from one person to one person. Each person is, at any time, one partner, one child, one mother or father. Even the relationship between doctor and patient, where many of the guidelines and policies are implemented, are between one person and another.

To me, this means that we need to better understand the dynamics of the individual. People as wholes, not parts.

The other day I heard Jim Pickett, a colleague in the rectal microbicides movement and a fellow Midwesterner in the U.S., use the term "waist to knee science" in reference to the research focus on viral transmission between genitals, basically, instead of all the variables that can lead to transmission in a sexual encounter.

In similar fashion, often when HIV discussions turn to women they go quickly to the (temporary) state of pregnancy rather than the totality of being female or all that it means to be a woman in this world. On the subject of pregnancy and reproduction, I find it tragic that the health of the mother seems to have been an afterthought in the equation of "success" of mother to child prevention. The focus is really on one event – the birth of a baby without transmission of HIV during that process – rather than to include all that happens before and after.

It has always been my understanding that what is best for any baby, HIV-positive or negative, is a healthy mother. Why has the focus not been on her? Why the baby without her?

I am concerned by the language of "sexual and reproductive health." In this building, in the research community, it seems to concern itself with conception, contraception, sexually transmitted infections – vaginas.

Down in the infield, in the Global Village, when the community talks about sexual and reproductive health we mean it to include things like desire, safety, pleasure, control, value, access to information...

I am doubtful meaningful research is possible in this important area unless the definition of "sexual and reproductive health" is one that is completely shared and is pursued as such.

Women are half the world's population. In the context of HIV/AIDS, now more than that. How is it then that we are regarded as a "special" population? How is it that a clinical trial of 25% women amounts to cause for celebration?

If you ever doubt that we are persistently at risk of being regarded as extensions of men, allowing data to be extrapolated to women from studies in men, or as a means of reproduction, imagine if the research status quo were flipped so studies were now to be 70 or 80 or even 90%

women – the opposite of what it is today. Or, frankly, even 60%, which would be representative of the epidemic now.

I, for one, have no trouble imagining the resistance to such a standard, which would threaten our “special” status and make us, well, people. In community activist settings, I have long resisted attempts to create women’s committees and segregate the issues. I believe that our issues are people’s issues – women are central to everything – and we all gain by investing in research that addresses women.

If we have the shared goal of reducing HIV infection in women and in our enormously threatened young women and girls, then we must commit to: 1) designing research that is relevant to women and girls, which requires shared understanding of “relevant”...which requires authentic engagement.

On the way to the march yesterday I met a German government policy official who does HIV prevention policy work but doesn’t know anyone with HIV. This would be funny if it weren’t a story common all over – that people making policy about this epidemic remain completely removed from the people of this epidemic.

You get the sense in some circles that HIV-positive women are “difficult” to reach. You’ll hear that we’re hard to enroll and retain in clinical trials, we have complicated lives, we have families to tend, we’re hidden...

Yesterday Gracia Violeta Ross from Bolivia described a process she used in her country to create a direct link between poor people living with HIV/AIDS who had very little reading and writing skill – the people many would say cannot be reached – to the policy-makers in government. They drew pictures of their experiences.

Drawing after basic drawing made it clear that, if testing isn’t accessible and free and anonymous, people won’t get tested. It was obvious that there are not enough physicians who treat HIV/AIDS, so people avoid hospitals and medical care because of stigma and judgment.

The pictures told the story and the story made an impact on the government of Bolivia. I found this an exhilarating example of what is possible.

2) making up for lost time in studying adolescent girls, in every way, starting yesterday.

3) including the community to be studied in the design of the research. I must say on this subject that tokenism is a real threat and it can inhibit the yield of good information. I’ve sat at too many tables with community members invited by the host who never open their mouths.

Personally, I think it’s hard to speak out if you don’t know what’s going on or, frankly, if you’re feeling grateful for being in the room. The problem is that whoever invited them walks away likely thinking they have now consulted the community, perhaps never appreciating the impact of the dynamic of the situation.

Also, authentic representation is a perpetual challenge in the community. I mentioned Frika Chia earlier – APN+ has tried to overcome this with the inclusion of surveys and interviews in their work in an attempt to safeguard inclusion and the diversity of perspective.

4) committing to community treatment literacy, particularly in the context of research. Research speaks a technical language and the people involved must be able to understand the language and translate it for their communities.

At this conference Mike Cohen said about preventive vaccine research that “stopping is not an option.” I think the same is true for attempts to create more meaningful research for women. The growing depth and breadth of the epidemic in women does not allow it.

The thing about research is that it is a perpetual process of piecing together imperfectly obtained bits of data in an attempt to create a more complete picture. There is no perfect research, so there is little to lose. There certainly is no better time to do it differently.

The APN+ survey that I mentioned, notably called “When asked, communities respond,” has a quote I’d like to read. A program director of a prominent research group said, what we have found in community after community is that the best response is a local response, an indigenous response. Country after country, this is true.

I believe this is also true for research – the best questions are local questions.

Thank you.