

*XIV Conferencia Internacional sobre el SIDA. Barcelona, 7-12 de Julio 2002*

## Tilting at windmills\*

**Mary Crewe**

Centre for the Study  
of AIDS  
University of Pretoria

In the time available, I wish to give some insights into the complexities of the work in this track and give a general overview of what was presented. I am doing this on the assumption that there will be a conference report and that a fuller version of this summary will be available for publication.

The theme of the conference is Knowledge for Committed Action. The strength of track E - and the strength of social science - is that it deals as a priority with the social construction of knowledge, and the ways in which understanding is created. Social science takes established debates, and subjects them to new theorized and empirical scrutiny. It thereby opens the way for greater understanding of the epidemic and what it is we are trying to do.

This imperative towards better understanding, while it has been obscure to others at times, is increasingly becoming recognized as the strength that must start to influence our knowledge and understanding of the epidemic and also direct how we amass new knowledge. In this respect it was heartening to observe how widely notions of context are being taken up and used to promote programme success.

But this critical perspective must also inform how we use knowledge. There is now a great deal of information about HIV and AIDS. There is a great deal of commitment and there is much action. But, given the realities of the epidemic that have been so harshly and relentlessly outlined for us again at this conference, we must ask the question: what is it that we need to know in order to get us past what seems to be the current impasse in finding a global response that will stem new infections, reduce stigma, ensure access to treatment and quality of care?

One Track E Symposium speaker from our session entitled "Brave New World: Thinking Faster than the Epidemic", noted that we risk ignoring the political

at our peril. It is clear that we are faced with a disturbing swing to simplistic and often authoritarian solutions. At the same time as the Global Fund is launched and starts to respond to requests, we have the largest and most powerful government in the world threatening to cancel funding for work that does not place itself in the context of heterosexual marriage before which there is to be abstinence. This is an act of silencing.

We have been faced yet again with many silences in this conference: the silence of many faith based organizations, the silences on HIV and AIDS as a security issue, the silences that still surround much of the lives and work of gay men, sex workers, sexual violence, institutions and injecting drug use.

It is true that many silences were broken at Durban, but the question we ask now is: where are the voices to speak for people in all of their diversity and how do we stop the silences from creeping back.

The titles of the sessions of Track E drew a great deal of attention. The Track committee chose them with care to ensure that in all the discussions taking place, the social context that structures and surrounds the issues under discussion were foregrounded. For example, in the session of sexual violence, entitled "Social Fury: Sexual Violence and Masculinity", the papers recognized there is more than individual men's proclivity for violent behaviour and, instead, investigated the cultural and societal forces that facilitate rape. For example, in a paper from South Africa group rape was found to be a way of men showing group solidarity. Similarly, in a paper from India, men used violence to enforce gender norms and women endured violence to fulfil gender expectations.

One of the cross-cutting themes in these papers was a sense that both "sexual violence" and "masculinity" are far more complex and multi-dimensional categories than has often been recognized in HIV/

Correspondencia:  
Mary Crewe  
mcrewe@ccnet.up.ac.za

\*Acknowledgements: To the team of rapporteurs for their contributions.

AIDS research. Greater nuance in the empirical and descriptive documentation of these categories, together with analytic and theoretical refinement, would appear to be an urgent priority in order to think more effectively about their impact, as well as to design programs promoting greater gender equity and reducing or mitigating the consequences of sexual violence.

Consistent throughout the Track E sessions was a need for greater understanding of the words and terms we use so lightly, for example, how should we speak now of women's empowerment? We were also asked to re-think the vulnerability of women and notions of risk. Papers from Zimbabwe, Angola, Nigeria and San Francisco showed how in various ways women have been able to create new networks of power and support that, at many levels, challenge the conventional stereotypes still used to describe them and their position within families, society and political structures.

Similarly, in a session entitled "Positively Pregnant", the emphasis was placed on affirmative aspects of women living with HIV being pregnant, and how this experience changed their relationships with medical support structures, their partners and families. For example, the abuse of the reproductive rights of women in Brazil came to the fore in the paper on how women in that country needed to challenge the orientation of biomedical practice toward the automatic sterilization of HIV-positive women.

From the session "In the Joint" came discussion on the issues around the identification of structural factors that contribute to risk and vulnerability as well as strength of a population within closed settings such as prisons and juvenile justice facilities. Challenging AIDS from behind bars was the theme of papers from Nepal, the US, Zimbabwe and Australia, which noted how prisons both reflected the power relations and vulnerabilities and gender imbalances outside of the prison, and also reflected the possibilities for change through the institutional setting itself.

In Durban, we heard how injecting drug use was fuelling the most rapidly expanding HIV epidemics ever seen, with explosive rates of infection being reported in Ukraine, Belarus and Russia. Sadly, this message has been repeated at this conference. Russia continues to provide the most devastating example of an epidemic out of control - the warnings of two years ago and our window of opportunity noted then is fast closing.

In the session "Needles are not just for threading", papers examined changing epidemics, changing

behaviours, changing contexts and changing responses. Social and economic turmoil provide fertile ground for rapid spread of both IDU and HIV. We heard of increasing HIV risk behaviours among Afghan refugee drug users in Pakistan in the wake of the War on Terrorism and of the role of IDU in the HIV epidemic of bankrupt Argentina.

Research is delving more deeply into the meanings and contexts of drug use beliefs and behaviours, as reflected in presentations that took us into nightclubs with HIV positive gay injecting drug users in Sydney and down slum alleys lined with heroin injectors in Hanoi.

In plenary we were disturbed by the news that IDU epidemics are moving into adolescent populations, such as in Russia, and in countries which were once considered "immune", such as Libya and Indonesia.

Whereas knowledge and evidence are critical for designing effective responses, we heard that research may be irrelevant for convincing politicians and the community to implement controversial harm reduction programmes-alternative approaches, such as activism, broad coalition building and political lobbying may be more effective in certain situations.

It was clear throughout the track sessions and discussions that we need to pay far greater critical and theoretical attention to issues of class, race, gender, sexuality and culture, if we are to understand the new and complex evolving epidemics and our responses to them.

"Turning Tricks" turned our attention to sex workers in studies from Uganda, South Africa, Nigeria and India. It was generally agreed that in much existing work with sex workers far too much attention has been placed on sex as the only risk factor and the only way in which sex workers are defined. This masks any understanding of their other roles and lives as wives, mothers, brothers members of wider society and friends. This was particularly clear in the reaction from the faith-based organizations through the ways in which they stigmatize and characterize sex work. This reduces sex workers to narrow "at risk" categories and fails to develop the social understandings of sex workers as participating citizens. Transactional sex is an emerging issue that need new ideas.

Forever young, the session on risk sexuality and youth gave new ways of how we interact with young people and their legitimate sexual interests. In studies from the US, Tanzania, South Africa and Peru we were introduced to how young people think about risk, sex, AIDS, gender and vulnerability and

highlighted again the need to look at all young people in this epidemic-not just those whom we feel are vulnerable or at risk.

This session coupled with that of Educating Desire showed the importance of positioning desire into education systems along with sexuality, love, pleasure and a life of integrity and honesty.

This kind of knowledge is important as they grow up practicing gender and learn to challenge and break the existing stereotypes and oppressions. It needs to be emphasised again as it was in Durban that gender sexuality and AIDS and the trans/formations that this allows are essential for both men and women and not for women alone. Studies from Zimbabwe, India, Cameroon and Tanzania pointed us towards seeing sexual practice and negotiation in new and fascinating ways through trans/generational sex, women marriages and sexual and economic emancipation.

There remain unacceptable and inexplicably high levels of discrimination against transsexual/transgendered people and studies have highlighted the need for diverse and appropriate language and race and gender responses.

Stigma was a strong theme throughout the conference and many sessions were concerned with ways to both understand it and address it from the UNAIDS and USAID meetings to the session on Stigma, Discrimination and Human rights.

Clearly there needs to be greater attention paid to the laws that exist to protect people and the creation of a social and political ethos to use these laws and ensure that they are carried out.

Stigma remains one of those intractable social problems that will require a determined effort to make sure that we are able to address it at every level and redress the multiple wrongs that have been and are inflicted on People with HIV and AIDS and their families.

In the session, "Man to Man", the continued importance of gay community involvement in and support for a securer sense of self and safer sex practice was highlighted in recent research in the USA, this together with sexual scripting offered ways to develop greater communication between gay men and in the wider community. It is clear that the stigma attached to, and denial of male-to-male sexual cultures and practice is an ongoing area that needs to be addressed.

Research in Russia suggests high levels of transactional sex among men and underscored by

the vulnerability that arises from the newness of such gay communities and the current economic difficulties in Russia.

Looking at the new economic commitments to HIV and AIDS programmes and prevention the question was asked why it is that we have been so strikingly unsuccessful to demonstrate to the world's financial elite that AIDS is an economic catastrophe. The need for a greater debate between activists and economists was highlighted by the request that we should stop demonstrating the negative effects of an epidemic that we have failed to control and rather start to demonstrate the beneficial impact of our interventions.

The session "acting out" showed that culture, art and performance remain strong ways through which social context can be understood and explained. Puppets from Mexico, Cultural weapons from South Africa, India, Peru and Uganda showed ways to address stigma and discrimination.

And finally as we are in Spain, it is appropriate to talk about "Tilting at Windmills", the title of the final Track E session on social theory and the epidemic. This highlighted how good theory and empirical social research can assist in uncovering assumptions, root out conceptual and disciplinary biases in both biomedical and social research, and how our reconceptualisation of both research and practice can be helped by the process.

The session explored research using theory on "social capital" in South Africa, the notion of "dynamic safe sex cultures" and policy development in Australia, the "social construction of HIV positive people in medical discourse and educational practice", and the involvement of "social networks" in program development, and a discussion of the "inadequacy of treatments optimism theory" in papers from North America.

## **Conclusion**

In conclusion we note that the proliferation of tracks here in Barcelona has unwittingly fragmented the gaze on the social aspects of the pandemic and diluted the analyses of responses to it. We support the more consolidated framework proposed for Bangkok.

Social science has become more accepted in the fields of prevention and IDU issues, and there has been less focus on epidemiology and behavioural interventions as the central ways of understanding these issues. Qualitative research is gaining greater

credibility in settings where traditional epidemiology and behavioural modelling have long reigned, and, consequently, the conceptualization of HIV risk and vulnerability is being revisited. As the demand for equitable treatment access grows, we will need to employ this kind of social research and its analytical frameworks more effectively to make a similar contribution to understanding and informing evolving treatment and care policies, approaches, and programming and evaluation.

We have heard how *scaling up* is an art not mathematics. We have also heard that scaling-up for prevention, treatment and care is critical for impacting on the epidemic. Art always requires an

understanding of techniques, materials, systems, context and their interactions. That's what social research and its many methodologies do well.

And finally with respect to the future between now and Bangkok we as social scientists have a responsibility to:

- deliver rigorous thinking to effect concrete action.
- promote programmes that include a broader and more complex range of groups, communities, populations and societies, and address poverty.
- ensure excellence in scientific understanding, tempered by concern for social justice and human rights.