Scaling up HIV testing: Are we ready to throw out human rights protections?

Joanne Csete and Richard Elliott Canadian HIV/AIDS Legal Network

XVI International AIDS Conference Toronto, Ontario August 2006





Urgent to scale up HIV testing access: VCT a response to rights abuses

Historically dominant client-initiated model (VCT):

- Confidentiality
- Consent, specific and informed
- Counselling, pre-test and post-test

3Cs meant to protect rights of people who were marginalized, stigmatized, criminalized



Calls for other approaches

Increasing call for more <u>provider-initiated</u> testing:

- "routine offer" (with or without <u>informed</u> consent, counselling)
- "routine testing" (test administered unless the person to be tested "opts out")



Questions considered

- What are the criticisms of the VCT approach raised by those who call for "routine" approaches?
- What are the human rights concerns that "routine" approaches raise?
- What research is needed to inform this debate?
- [J Csete and R Elliott, HIV/AIDS Policy and Law Review 2006; 11(1):1, 5–9; available at www.aidslaw.ca]



Current WHO/UNAIDS policy

Recommends routine offer of test to:

- Pregnant women
- People diagnosed with other STIs
- Asymptomatic people where HIV highly prevalent and treatment available

Even with routine offer:

- Sufficient pre-test counselling to ensure informed consent
- People must know they have a right to refuse



Calls to rethink VCT

(De Cock et al., 2002, "Shadow on the continent")

- VCT with 3Cs is too slow and costly to respond to the emergency of AIDS
- HIV/AIDS awareness already very high in highly affected countries → less need for counselling
- Human rights protections around HIV testing add to stigma; "normalizing" HIV testing will reduce stigma
- VCT undermines social justice if it restricts people's access to testing



VCT's basis in human rights

- Informed consent derives from right to security of the person, right to receive information
- Pre-test counselling contributes to protection and fulfillment of these same rights; post-test counselling imparts essential information
- Confidentiality of results and of the fact of seeking a test is part of protecting and respecting the right to privacy



Responsibility to minimize abuse

General Comment of UN Committee on Economic, Social and Cultural Rights:

Right to health includes responsibility of governments to minimize discrimination and other abuses that may be associated with a health service or program.



Preventing abuse linked to testing

From WHO review of 17 studies, Africa & Asia: [Medley et al., *Bull WHO* 82(4):299–307, 2004]

- 4% to 28% of women reported negative outcomes following disclosure of their status.
- 2.5% to 14.6% reported facing violence as a reaction to disclosure of their status.
- Pre-test counselling offers opportunity to identify those at highest risk of abuse and help women take measures to minimize it.



Testing uptake as indicator of success?

What if those captured in routine testing

- are not well prepared for the test?
- do not have adequate information to understand what HIV means for their lives?
- fear HIV because they have little information?
- have little sense of how to disclose or talk about their status?



Testing uptake as indicator of success?

Successful testing policy would strive to:

- minimize negative outcomes (including depression, abandonment, suicide, violence, other abuse);
- instill confidence of patients in health-care providers, essential for further care;
- preserve value of testing experience as a prevention tool.



Necessity of pre-test counselling?

- Qualified counsellors in short supply; this is a policy and resource question.
- General awareness of HIV is not the same as the knowledge, aided by counselling, that can assist behaviour change.
- Was counselling ever adequately funded in period when VCT is said to have failed?
- More research needed on elements of pre-test counselling that can reduce abuse or identify those at high risk of abuse.



'Routinization' and stigma

- Evidence that making HIV testing 'routine' reduces stigma? That it reduces the deep disdain and abuse faced by criminalized and marginalized persons?
- Stigma and abuse alive and well: few efforts to address it.
- Lack of confidence in health system when people realize they were tested without consent.



Conclusions (1)

- Ensuring access to HIV testing with counselling, informed consent and confidentiality is part of human rights obligation of governments.
- Testing services should strive to minimize abuse and maximize benefits, including link to treatment.
- Greater investment in VCT is consistent with human rights obligations.
- More documentation of experiences of those offered testing is needed.



Conclusions (2)

More research needed on:

- How pre-test counselling and other elements of testing can most effectively contribute to reducing adverse outcomes
- Impact of 'routinizing' testing on stigma
- Way in which routine offer or routine tests are experienced by people in real life, especially where people are unlikely to challenge recommendations of health professionals



Recommendations

Allocation of resources to:

- strengthen and scale up VCT with 3Cs and link to care, treatment, support;
- monitor emerging provider-initiated experiences, including range of outcomes beyond testing uptake (governments must allow independent research);
- ensure participation of people living with HIV, women, marginalized persons in testing policymaking;
- fill research gaps.



Universal access impossible without human rights

- Criminalized people among those most affected by AIDS
- Criminalization of HIV transmission on the rise in many countries
- Those who call for "routine testing" frequently say there should be protection against stigma and discrimination, but where is the scale-up plan for that?



Social justice vs. human rights?

What kind of social justice is possible without human rights?

(Pitting social justice against human rights is a low point in this debate.)



Human rights and HIV/AIDS: Now more than ever!

About the Canadian HIV/AIDS Legal Network

The Canadian HIV/AIDS Legal Network (www.aidslaw.ca) promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally, through research, legal and policy analysis, education, and community mobilization. The Legal Network is Canada's leading advocacy organization working on the legal and human rights issues raised HIV/AIDS.

