

Author(s): Tim Rogers, 2009

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Promoting the
Empowerment of
Communities to Fight
HIV Through
Information Exchange

Tim Rogers
Director, Knowledge Exchange
October 2009

www.catie.ca



Introduction to HIV

- Human Immunodeficiency Virus – weakens your immune system
- If untreated, HIV can cause AIDS (Acquired Immune Deficiency Syndrome)
- There is no cure for HIV and there is no vaccine that can prevent HIV infection
- There is treatment for HIV that can slow and even reverse the progression of HIV, but daily adherence is crucial, treatments can have side effects



HIV Transmission

- HIV is NOT transmitted through casual contact—kissing, sneezing, toilet seats, insect bites
- Only five fluids contain enough HIV to infect someone: blood, semen, vaginal fluids, anal fluids, breast milk
- HIV-infected fluids must come in contact with broken skin or mucosal membranes (the wet linings of body cavities, such as vagina, penis, rectum) in order to infect someone



HIV Prevention

Successes

- HIV is no longer transmitted through blood products, if properly screened
- HIV transmission from mother to child is rare (<1%) if the mother is diagnosed and treated for HIV during pregnancy and breast feeding is avoided (unfortunately not all mothers have access to care)



HIV Prevention

High risk modes of transmission

- Sex without a condom
- Sharing needles and some drug equipment

You can have HIV and not know it

- Approximately 20% of people living with HIV in the US do not know their status (>200,000 people)

Centres for Disease Control estimates, 2006 at www.cdc.gov



Who is living with HIV globally?

33.2 million people (as of 2007)

- 67% live in Sub-Saharan Africa

Adult HIV prevalence rates:

- Sub-Saharan Africa 5%
- Caribbean 1%
- US 0.6%
- Latin America 0.5%
- Canada 0.3%

UNAIDS estimates, 2007 at www.unaids.org



Who is living with HIV in Canada?

Populations vulnerable to HIV in Canada

- Gay men and other men who have sex with men (40-70 X higher prevalence than general population)
- People who use injection drugs (50 X)
- People from endemic countries (12 X)
- Prisoners (9 X)
- Aboriginal communities (3 X)

HIV in Canada: Trends and Issues for Advancing Prevention, Care, Treatment and Support through Knowledge Exchange, CATIE: 2008 at www.catie.ca



HIV Vulnerability

HIV disproportionately impacts marginalized communities (less access to prevention, care, treatment and support services)

Need to address “Social determinants of health” – income, social support networks, access to health services, social environments, etc

HIV-related stigma and discrimination is huge issue

Fight against HIV is intimately connected to fight for human rights (see Jonathan Mann)



Further reading on HIV

What you need to know about HIV and AIDS

www.catie.ca/aidscourse.nsf/fmCourse?OpenForm

HIV in Canada: Trends and issues for advancing prevention, care, treatment and support through knowledge exchange

www.catie.ca/pdf/Canada/HIV-in-Canada_ES.pdf

Managing Your Health: a guide for people living with HIV

www.catie.ca/eng/myh/toc.shtml



CATIE's mission

CATIE champions and supports innovation and excellence in knowledge exchange for the prevention of HIV transmission and the care, treatment and support of people living with HIV



CATIE's mission

“Knowledge”

- Understanding possessed by someone

HIV knowledge can come from:

- Research processes
- Reflection on accumulated experience
- Wisdom gained from everyday living, observation, dialogue and knowing how to do things
- Collaborative learning



CATIE's mission

“Knowledge Exchange”

The process of building, sharing and acting upon knowledge

Interactive process for problem solving that involves:

- Gathering and assessing knowledge
- Synthesizing, translating and adapting knowledge to specific contexts
- Disseminating knowledge
- Applying knowledge to improve practice and health care



CATIE's mission

- Collaborating with and building the capacity of front line organizations to use knowledge effectively to respond to the epidemic
- Supporting and connecting people with HIV, other individuals, and organizations to develop, synthesize, share and apply HIV knowledge
- Acting as a central contact point for the flow of comprehensive, accurate, unbiased, timely and accessible HIV information and community-based knowledge



CATIE's Audiences

- **People living with and vulnerable to HIV/AIDS**
- **Community intermediaries:**
 - Friends, family
 - Support workers, counsellors, outreach workers
 - AIDS service organizations
- **Healthcare intermediaries:**
 - Physicians, nurses, pharmacists, complementary therapy practitioners

Focus on community-based knowledge exchange



CATIE is a Learning Organization

- Educational Programs (in-person and e-learning)
- 1-800 line & email (support, information, referrals)
- Web sites (main site, youth, nurses, multilingual, hepatitis C)
- Publications
- Building the capacity of community networks, programs and services
- National knowledge exchange broker



Further Reading on CATIE

**Building Excellence in HIV Knowledge Exchange:
CATIE's strategic plan 2008-2011**

www.catie.ca/pdf/StrategicPlan_2008-2011.pdf

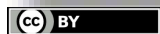
*The Canadian AIDS Treatment Information Exchange in
Moving Moving Population and Public Health
Knowledge into Action* www.cihr-irsc.gc.ca/e/30751.html#c

Power to the people in **The Positive Side**

www.positiveside.ca/e/V8I1/Power_e.htm



Protest March



CATIE



Community Empowerment

Treatment information exchange was a foundational element of early AIDS activism

- People with HIV disseminating treatment information in their communities (medical article reprints, factsheets, treatment news bulletins, local newspaper columns, community forums, “word of mouth”)

CATIE started by AIDS ACTION NOW! IN 1991

- Core value that people living with HIV/AIDS be involved in all aspects of organization
- Empower individuals to take charge of their health care
- Expose barriers to treatment and care
- Expose systemic problems in HIV research and policy
- One of many such organizations around the world

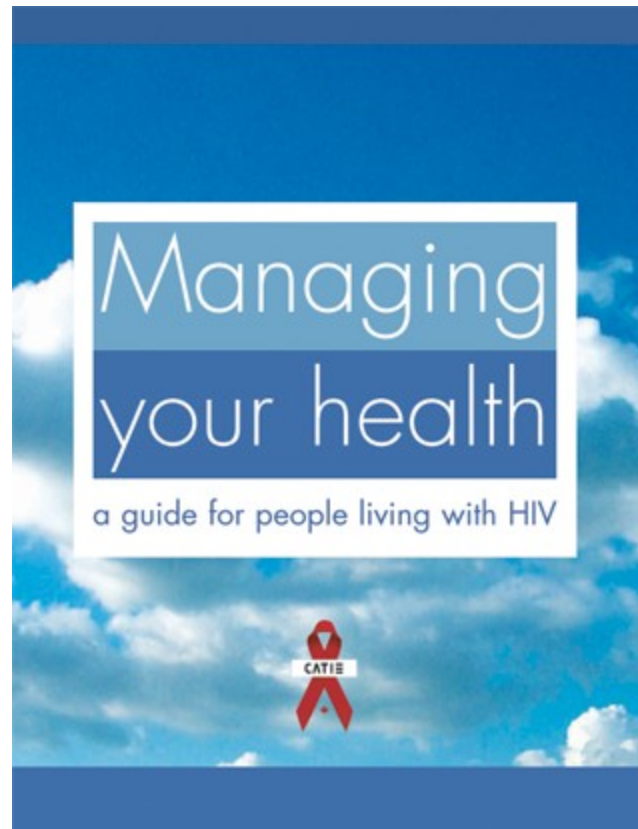


Examples of Community Empowerment

- “Democratization” of treatment information
- Community engagement in HIV research
- Body mapping
- Building communities of practice



“Democratization” of treatment information



CATIE



“Democratization” of treatment information

People with HIV are active partners in decisions about their health

- Deconstruct the “authoritarian” model where physicians are the gatekeepers of knowledge

Holistic notion of treatment

- Beyond the “medical model” of disease
- Value lived experiences
- Value holistic approaches to health: nutrition, complementary therapies, emotional health, spiritual health
- Recognize the social and environmental context of living with HIV

The “Exchange” of treatment information

- Different types of expertise need to be valued (eg. experiential knowledge, clinical knowledge, evidence-based knowledge, community knowledge)



“Democratization” of treatment information

Examples of CATIE Initiatives

- Managing Your Health
- The Positive Side
- Pre*fix: harm reduction for + users
- Information services by and for PHAs
- Practical Guide to Complementary Therapies

These examples can be found at www.catie.ca



“Democratization” of treatment information

Quality is important

- **Accurate** – timely, evidence-informed, unbiased, comprehensive
- **Trusted sources** – the messenger is important
- **“Speaks to me”** – practical, contextual, meaningful, community-aware
- **Shared experiences** with other people with HIV :
What did it feel like? How did you decide? Who did you turn to?



“Democratization” of treatment information

One Size does not fit all

- **Multiple channels** (one-on-one, print, Web-based, multimedia, workshops)
- **Multiple health literacy levels**
- **Diverse communities and populations** (Gay men, women, youth, Aboriginal people, injection drug users, inmates, multiple languages)
- **Diverse capacities to receive information**



“Democratization” of treatment information

Information is relational

- **Engage multiple stakeholders** (people with HIV, researchers, clinicians, community leaders, support workers)
- **Support information exchange networks** (connecting different types of knowing, building networking opportunities, providing training/support to “knowledge workers”)
- **Long-term partnerships** with vulnerable communities are crucial for building trust and for creating relevant informational resources



Community engagement in HIV Research

Communities infected and affected by HIV should be active partners in the research process (Montreal AIDS conference 1989)

- Selecting priority questions for research
- Ensuring ethical conduct of research with vulnerable populations
- Making results of research available and meaningful to those who can benefit from them (new treatments, emerging side effects, community vulnerability)
- Using information to advocate for social change (access to care, harm reduction)



Community engagement in HIV Research

Examples of CATIE Initiatives

- CATIE- News: Plain-language research bulletins that make findings meaningful for people with HIV and their communities
- Community forums: involve both researchers and community presenters (in person, teleconferences, web conferences)
- Learning Institutes: support for community members to participate in scientific conferences (pre-conference learning opportunities, networking support during the conference and support for sharing post-conference learning in their communities)



Community engagement in HIV Research

Examples of CATIE Initiatives

- “Virtual library” of key information/education resources that are high quality and specific to the needs of community
- Supporting individuals and organizations to connect with existing research, advocacy and information sharing networks
- Skills building and informational support to individuals and networks involved in advocacy (eg. how to find, assess, interpret and communicate research information)
- Community-based research – grew out of anti-oppression movement in Latin America [see Paulo Friere]



Combining different ways of knowing: Body Maps



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Combining different ways of knowing: Body Maps

North-South partnership between CATIE and the Regional Psychosocial Support Initiative (REPSSI) of Southern Africa

Combine arts-based workshop developed by REPSSI with treatment information workshops developed by CATIE

Innovative method to make HIV information accessible and meaningful

Work with African women living with HIV in Tanzania, Zambia and Canada

Focus on plain language, low literacy, culturally appropriate information



Combining different ways of knowing: Body Maps

Developed “Tracing Books” as a way to monitor symptoms and well-being and to communicate with health care providers who speak a different language

Expanded to workshops with other populations living with HIV: Aboriginal men and women, gay men

Developed a training program so that community-based organizations in Canada and Africa can do this workshop on their own

Working with researchers to evaluate outcomes and understand how this tool can help people living with HIV



Combining different ways of knowing: Body Maps

For more information on Body Mapping visit
<http://www.catie.ca/bodymaps/index.shtml>



Building Communities of Practice

Communities of Practice

- Collective, informal networks that support “professional practitioners” in their efforts to develop shared understandings and engage in “work-relevant” knowledge building [Hara 2009 with quotes added]
- Learning (knowledge sharing and building) to effect change
- Focus on knowledge to action



Building Communities of Practice

“Knowledge” versus “Information

- Tend to think of information as “out there”
- *Someone’s* understanding (embodied, contextual, sometimes tacit)
- Involves *social relationships* (collective, dependent on personal and organizational relationship)
- Increases through *processes* (the flow of knowledge through networks/communities; the building of knowledge through collaboration; collective assessment of value)



Building Communities of Practice

Connecting people who are currently working in “silos” of expertise

- programming, research, policy development, lived experience
- community knowledge, biomedical knowledge, “how-to” knowledge, political knowledge

Understanding and building on existing knowledge sharing networks and processes

Developing support and infrastructure to increase sharing and collective knowledge building



Building Communities of Practice : Examples

CATIE's Programming Connection

- Forum for sharing knowledge about programming
- Develop series of “good” practices as examples
- Develop narratives that show the inter-relationship between different areas of knowledge

Challenges

- Filtering good case studies is important but how can we collectively decide what is “best”?
- What types of knowledge need to be shared?
- What structures need to be in place for front line workers to describe their programs in a way that is conducive to knowledge sharing
- How to connect with research evidence about what “works”?
- Building common vocabulary (Plain language)



Building Communities of Practice : Examples

Developing an interactive “knowledge” commons

- Central repository of “knowledge objects” (documents, videos, images, etc.) for sharing among researchers, policy makers, front-line workers and community members
- Centrally “controlled” versus community “controlled”
- Need to create an overarching information architecture that provides a place for everyone and shows inter-relationships between silos of knowledge
- Need to establish how to work with existing expertise (individual, community, organizational)
- Should everyone have access to all the documents?



Building Communities of Practice : Examples

Facilitating collective knowledge building

- Gap between biomedical science of prevention and current on-the-ground programming
- Addressing gap requires exchange among many silos of knowledge to come to new, collective understandings
- “Deliberative dialogue” as a mechanism to collectively address a problem at a strategic level



For Further Information

Visit www.catie.ca

Thank you!