



Stigma in Health Care for Persons Living with HIV

**Nancy Edwards, Judy Mill, Randy Jackson, Wendy Austin,
Lynne MacLean, Frances Reintjes, Claudette Dumont-Smith,
Lynne MacLean**

**International Society for Equity in Health
Adelaide, Australia
September 12th, 2006**

Purpose of Research



- ...to explore the experience of stigma among individuals with HIV illness;
- ...to develop an intervention for the provision of health services to persons with HIV that mitigates the impact of stigma; and
- ...to optimize access to health services for this population.

Design and Methods



- Participatory action research
- Edmonton and Ottawa sites (n=11)
- In-depth interviews with 33 individuals living with HIV
 - 16 Aboriginal, 17 non-Aboriginal
- Interviews and focus groups with health care workers
 - 27 HC workers including: physicians, nurses, social workers, psychologists, dentist
- Analysis (audio-recorded, transcribed, coded using QSR*N6 to identify major themes)

Key Findings



- Stigma is dynamic and shifting
- Multi-level stigma: societal, health care environment, client-provider, client-community and client-client
- Embedded stigma and nested stigma are core elements

Stigma is dynamic and shifting



- Changes in the experience of stigma:
 - in rural and urban health clinic settings
 - with health care providers and social service workers
 - among Aboriginal communities
 - with friends and family
- “We’re going to make sure that nothing happens to you. So the second class citizen was taken away...”

Multi-level stigma



- Client-community:
- *"These landlords, they were Natives too...they were really gossiping about me...they were telling other people! 'Stay away from her, she has AIDS'"*
- Client-family:
- *"I noticed my cousins...put me down...only when they're drunk 'Get outta here. You're f...ing AIDS-infested'"*

Multi-level stigma



- Client-provider:
- *"When I was in the hospital...I don't know, they [nurses] were kind of mean to me."*

Nested stigma



- *"It's the stigma within the stigma 'Cause, oh another drunken Indian. Oh, and it's a faggot Indian...".*
- *"There's more stigma in my life right now with regards to being a drug addict that there is in my HIV and Hep C status".*

Layering of Stigma



HIV-positive Aboriginal Participant

"I just didn't want to be put in that category (HIV positive) because I was already dealing with a lot of other issues being - one, being Native, [pause] two, being in jail because I'm, you know, a Native. So, [sighs...] I didn't want to be ... black labeled."

Embedded stigma



- Multiple traumas
- Hierarchies of power and control
- Organizational and system co-morbidities

Embedded stigma



- Multiple traumas
 - Living on the street
 - Experience in prison
 - Losing jobs, friends, partners, family

Embedded stigma



- Hierarchies of power and control
 - *“I was selling cars for a living....if I needed a blood test...I never heard how much it costs. But because I’m now on [disability] and I’m living in the inner city...I get told that ‘Well, we’d send for another test but boy are those expensive.’ What is THAT man!. This is my health. I don’t want to hear about how expensive it is.”*

Embedded stigma



- Hierarchies of power and control
 - *“It a shame that they hold HOW you live against you, instead of it’s your medical condition, it’s well, you’re just living on the street and you can wait. You’ve got no home to go to – that’s their thinking. It’s really bad. I’ve had clients go down there and sit for hours with a dental extraction that might have to be done and come back 8, 9 hours later still not seen.”*

Embedded stigma



- Organizational and system co-morbidities
- *"I should also forewarn you that I have HIV and Hep C." And she comes back and said 'Well I just checked and our computers aren't hooked up to the main terminal to give the okay for your insurance plan'."*

Embedded stigma



- **Organizational and system co-morbidities**
- *"I come from a small community, so I was referred when my partner first came to live with me down there. The doctor just switched him off [to a small city] and told him that he's not even going to make a file. He's not even going to document it 'cause you live in this small town and I can't guarantee that people aren't going to find out."*

Embedded stigma



- Organizational and system co-morbidities
- *“On the unit, they had like a day-timer board on the table, and if you looked at it you could see everybody’s name and your assigned cell. Well, above the ones that were positive they had ‘HIV positive’ written. You know? Hell!”*

Elements of stigma: A socio-ecological Perspective



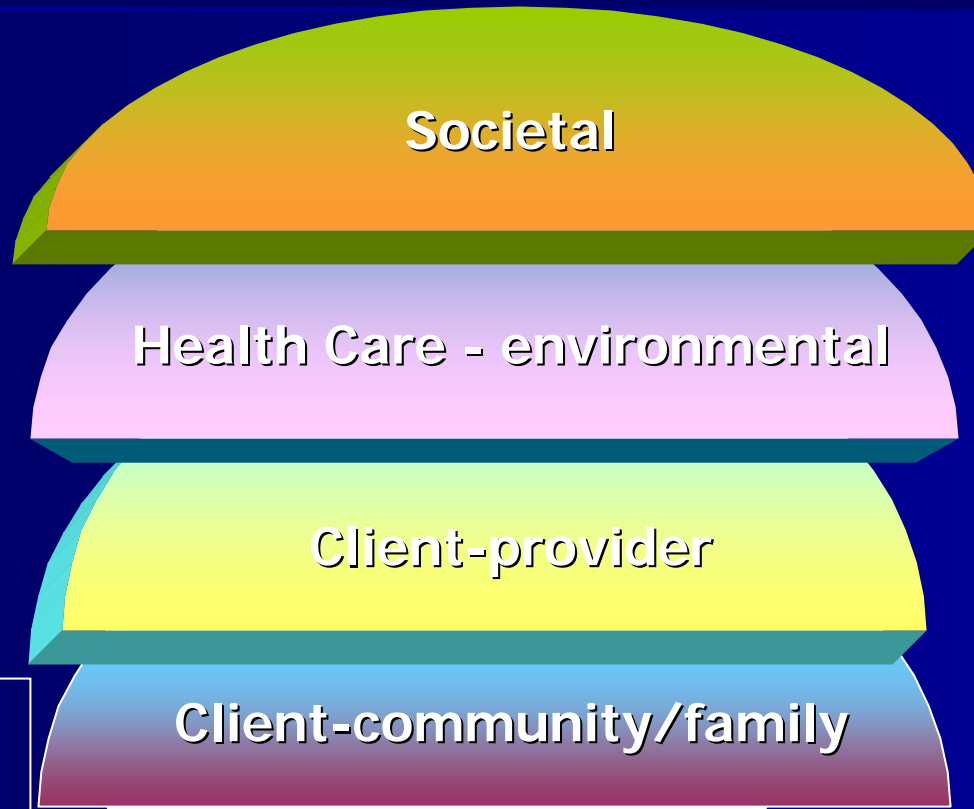
Dynamic shifts

Nested Sigma

- > Relational ethics & relational dynamics
- > Communication & confidentiality
- > Fatigue-weariness

Embedded Stigma

- > Multiple social traumas
- > Hierarchies of power & control
- > Organizational & system co-morbidities



• **Cross-system mobilization, sensitization & recognition**

• **Surface & acknowledge stigma**

• **Advocacy**

Conclusions and Recommendations



- Several key intervention approaches are needed to address the complex and dynamic nature of stigma
- Core strategies include:
 - Cross-system recognition
 - Sensitization
 - Mobilization and advocacy

Acknowledgements



- Funding was provided by the Canadian Institutes of Health Research.
- The research team and advisory committee members acknowledge the collective wisdom of study participants.