

**Self-stigma:  
An unspoken  
world of  
unspoken  
things**

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If I don't think **I'm bad**, why  
would I think you think **I'm bad**?

- Enacted stigma/discrimination
  - Social stigma/perceived stigma/felt stigma
  - Self-stigma/internalised stigma/internal stigma
- Why language matters?

- HIV-related self-stigma: negative self-judgements resulting in shame, worthlessness and self-blame adversely affecting the health of a person  
*(Kalichman et al., 2009)*

Name it



• Consistently, people living with HIV stigmatise themselves more than HIV negative people do – up to three times as much (GNP+, et al, 2011)

Where is stigma greatest?

		People living with HIV	General public	
South Africa (Simbayi, et al, 2007)	Feel dirty	27%	10%	Think PLHA are dirty
	Feel guilty	41%	13%	Think PLHA did something to deserve it
	Feel ashamed	38%	16%	Think PLHA should be ashamed
Ireland (SOSC, 2007)	Think PLHA are viewed negatively	84%	54%	View PLHA negatively

What the evidence says?

• **Ukraine Stigma Index Study**, of 1500 people interviewed 82% of respondents experienced various negative feelings towards themselves:

- 58% blamed themselves: 47% felt guilty
- 38% had low self-esteem: 37% felt ashamed
- 9% felt they should be punished: 8% felt suicidal

• **Scotland Stigma Index Study**, of 163 people interviewed, 40% reported feeling shame, 44% feeling guilt (Scotland): 39% of people living with HIV in Scotland isolated themselves from friends and family

• **Moldova Stigma Index Study**, 401 people – 46% feel ashamed, 45% feel guilty, 54% blame themselves

• **Asia-Pacific Stigma Index Study** analysis of 4395 people from nine countries:

- 75% of people in Pakistan saying they were ashamed of their HIV status to 54% in Sri Lanka

• **Rwandan Stigma Index Study**, 45% said they were ashamed

How bad is self-stigma?

- Objectives
  - Explore and examine core beliefs underlying self-stigma among people living with HIV;
  - Better understand self-stigma among people living with HIV;
  - Make recommendations for possible interventions to address self-stigma
- Methodology
  - Phenomenological qualitative approach (beliefs & meanings)
  - 17 participants all living in Ireland
    - 11 Irish-born, East, South, West Africa and Central and East Europe
    - Semi-structured interviews, written statements and participant observation
- Open Heart House and Trinity College Dublin

### 2012 study: Identifying and Exploring Core Beliefs Underlying Self-stigma among People Living with HIV & AIDS in Ireland

- Disclosure, non-disclosure and secrecy
- Sexuality, sexual pleasure and intimate relationships
- Negative self-perception
- Illness, disease and death

### Breaking it down

<p><b>Fears</b></p> <ul style="list-style-type: none"> <li>• Rejection, being labelled and ridiculed, being betrayed, disclosure among family</li> </ul> <p><b>Consequences of non-disclosure and secrecy</b></p> <ul style="list-style-type: none"> <li>• Social exclusion</li> <li>• Secrecy, two realities, confidentiality feeding secrecy</li> </ul> <p><b>Perception of thoughts of others</b></p> <ul style="list-style-type: none"> <li>• Negative perceptions</li> <li>• Extreme sensitivity</li> </ul>	<p><b>Self-abasement (degrading oneself)</b></p> <p>Dirty, shame, smelly, ashamed, contagious, useless</p> <p>Different</p> <p>Feeling less than</p> <p>Hopelessness (suicidal, depressed)</p> <p>Restricted agency (things I can't or won't do)</p> <p>Not having a child, not being able to find work of preference, not being able to travel, having to choose friends carefully, not being able to find a partner.</p>
<p><b>Sexual pleasure and desire</b></p> <ul style="list-style-type: none"> <li>• Fear of contagion, guilt and lack of energy</li> <li>• Unable to relax</li> <li>• Not enjoying sex – oral sex and touching</li> </ul> <p>Not feeling sexually free</p> <p>Disclosure and intimate relationships</p> <p>Fear of rejection</p> <p>Ending relationships</p>	<p><b>Medication and medical care</b></p> <p>Guinea pig, negative side affects, chronic pain and fatigue</p> <ul style="list-style-type: none"> <li>• Illness, health, disease and death</li> </ul> <p>Fears of being sick and dying, perceptions of eradicating disease</p> <p><b>Fear of contagion</b></p> <p>Fears with intimate partners, children, grandchildren</p> <p><b>Negative body image</b></p> <p>Losing weight, gaining weight, swollen stomach, shrunken limbs</p>

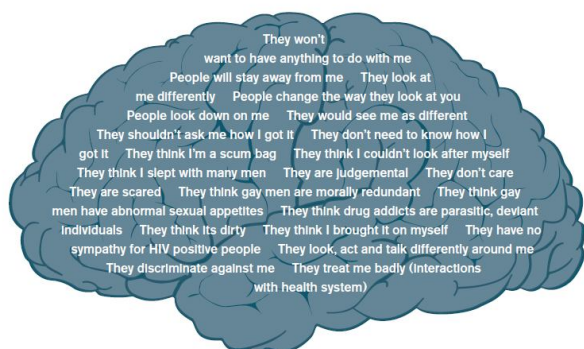
This is a punishment from God. I can't touch other people. I can't use the same utensil in the house. I feel unclean. I am an 'undesirable'. I am done. I am ashamed. People can see straight through me. I am useless. I am dirty. I am not at ease with myself. I am angry. I have a burning rage inside that could burst at any minute. I'm dangerous. I can't handle it. I'm alone. I have no one to talk to. I have a low self-esteem. It was self-inflicted. I am smelly. I am a terrible mother. I am a deserter. I am a disgusting person. I don't deserve anything. I am toxic. Something is eating away at me. I feel a little less every day. I'm less than I'm less of a person. I'm less human than everyone else. I don't deserve to be loved. I deserve it. I won't get the job. I'm inferior. It's really very hard being HIV positive. I feel a burden to people. I have changed.

(participants in Ferris France, N., 2008)

*'It's great when I'm here, when I'm in Open Heart House, cause I'm with like me own. But it's different when I'm outside, I try, you know, I'm getting better, but it's very hard... because I, in me head I know I'm just the same as everybody else, and I don't deserve, you know, no one deserves... but that dirty feeling still stands, no matter how much I wash, or how many clothes you buy, or how pretty you look, inside your'e still that, I don't know what you call it, worm picking away... some days like I feel toxic, [...], it's like as if there's something eating away from the inside that no one else can see but every day I feel a little bit less, like I've changed, you know, you change when your'e diagnosed, and it's not what people said to me, but it goes back. I really believe, it's an unspoken world of unspoken things'*

(participants in Ferris France, N., 2012)

People with self-stigma were **half as likely to disclose** their HIV status to their partner and less than half as likely to disclose it to their family (Kaichman... et al., 2009)



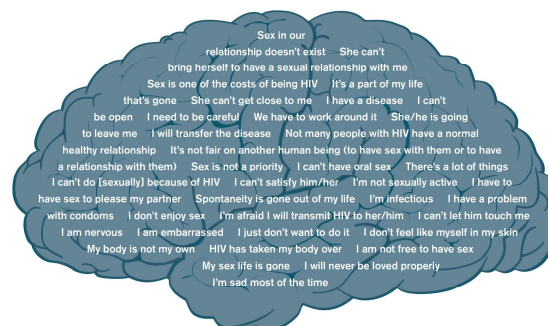
(participants in Ferris France, N., 2012)

*“They think you are a migrant and sponging off resources, or a gay man who’s morally redundant anyway, or a drug addict...parasitic deviant individuals”* (participant in Ferris-France, 2012)

- I can't have a child
- I can't get a job
- I can't find normal work in places of my choice
- I don't get any opportunity at work
- I can't work in certain companies
- I can't travel where I want
- I can't share my personal items
- I have to choose my friends carefully for the rest of my life or chose to stay alone

## Restricted agency

(participants in Ferris France, N., 2012)



*'my sex life, like he doesn't say it, but I feel it, the intimacy you know is gone. The, you know, the experiment, the stuff, all that's gone, it's just basic with the condom'*

(participants in Ferris France, N., 2012)

- Self-stigma may help justify not disclosing HIV status, as well as reinforce choices to limit life choices
- Self-stigma may act as a protective mechanism, so that if HIV positive people believe negative thoughts about themselves, they won't be hurt when hearing them from others.
- Self-stigma may serve a function in reinforcing the person as a victim justifying placing the blame on someone else which in turn takes the responsibility or sense of personal agency away from the person living with HIV

## Functions of self-stigma

- Community involvement, professional development and education
- Personal development, inner work and positive attitude
- Connection to others and sense of belonging

## Coping strategies

- Community involvement, professional development and education
- Motivated to go back to school/college
- Engaged in community work supporting other people living with HIV
- *I would have never ended up in a job like, if I had never become HIV positive [...] and it just gives me great joy to sit with somebody who is in great despair and desperation and to say to them, I genuinely know what you are going through, I genuinely know it's going to get better for you*
- *Get in there and get yourself involved get yourself down to actually helping other people and it will do a lot for you'*

## Coping strategies

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- Personal development, inner work and positive attitude
- *'... I believe that I'm more accepting today actually fully accept who I actually am, now...it's a tiny part of who I am so it doesn't stop me from doing absolutely anything, I have full acceptance of who I actually am today. I came out of the whole addiction side of it, I worked on personal development and doing a lot of work on myself, a lot of internal work and it brought me to where I actually am today, so.. I'm ok, you know, with who I am today'(C).*
- **The majority of participants could find some positives in being HIV positive**, however small,
  - *whereas I used to get worked up about things, frustrated, angry with people, now I'm just chilled you know, I do a lot of relaxation and all that, so thats, thats where I am now (G).*

## Coping strategies

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- Few approaches exist to support people to address self-stigma, despite the negative effects (*Kalichman, 2009*)
- 2011 systematic review found surprisingly few intervention studies aimed at reducing HIV-stigma (*Sengupta et al, 2011*) not to mention self-stigma
- While recent studies are highlighting high levels of self-stigma, no specific programmatic recommendations are made

## Highlighting the gaps

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More of the **same** is not going to work

We need to think **out** of the **box**

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### Evidence-based programmes and interventions

- Stress-management interventions including cognitive behavioural interventions as well as medication, mindfulness and relaxation-based approaches, i.e.,
  - Cognitive Behavioural Therapy (CBT).
  - **Inquiry-Based Stress Reduction (IBSR): The Work of Bryon Katie.** A simple, but very powerful technique of identifying stressful beliefs which enables participants to question their beliefs and through the process experience the opposite of what they might originally believe  
*(November 2013: intervention study currently underway in Zimbabwe with Trocaire and the Zimbabwean Network of People Living with HIV/AIDS, ZNNP+).*
- Facilitated peer-support groups
- Production of a practical skills-based toolkit for people living with HIV on self-stigma using '*HIV and self-stigma Core Belief Sheet: A practical tool for designing interventions to support people living with HIV*' a key output produced from this research study

Where to from here?

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### Advocacy

- We need to advocate for self-stigma – we need to ensure that it is recognised as a significant barrier to treatment, to patient care, to quality of life and that it is distinct to social stigma.
- An international meeting of stigma experts to focus on possible interventions and also design a clear research agenda moving forwards.

### Research

- More studies on self-stigma, as distinct from social stigma
- Analysis of Stigma Index Reports on self-stigma
- A study to better understand the functions of self-stigma to the individual
- Studies into the effects of and potential efficacy of mindfulness programmes for HIV self-stigma.
- More studies into the experiences, beliefs and strategies around sexual pleasure and intimacy among people living with HIV and AIDS
- Further research into self-stigma and coping factors of people living with HIV, such as childhood experience, community involvement, inner work, altruism



If I don't think I'm bad, why  
would I think you think I'm bad?

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**Be the change** you want to see in the world.....As a man **changes his own nature...** so does the attitude of the **world change towards him**

- Ghandhi

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