HIVOICES

Residential workshop and social research on HIV and sexual identity

Emanuele Pullega, Raffaele Lelleri
A New Training Path for HIV+ MSM, Focused on Peer-Group Here-and-Now Dimension
Background

- HIV is not only as a matter of prevention.
- Well-being and health for people living with HIV is not just a medical matter, but it is also a social-relational matter.
- Among HIV+ MSM, which is the connection between internalized homophobia and the difficulty to get a satisfactory level of one's own identity’s acceptance and visibility as HIV+ MSM?
Workshop presentation

• **What:** 4 intensive residential workshops in a protected and HIV status and sexual orientation pro-active environment.
• **Where:** an equipped country house catering for training groups in the Appennini Mountains.
• **Who:** gay and bisexual men living with HIV (around 20 per each group).
• **Timing:** during 2 and a half days, participants alternate informal times of cohabitation to formal training sessions (9 sessions of 2 hours each).
• **Recruitment:** Arcigay internal (web sites, social networks, notice-boards, face-to-face contacts) and external (press bulletins, articles on LGBTQ magazines) media.
• **Organizer:** Cassero Salute - Arcigay Bologna, Italy.
• **Trainers:** Filippo Porcari and Emanuele Pullega.
Already held training path

<table>
<thead>
<tr>
<th>FIRST STEP LAB</th>
<th>SECOND STEP LAB</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIVoices 1</td>
<td>Sono Sieropositivo</td>
</tr>
<tr>
<td>September 24-26, 2010</td>
<td>September 09-11, 2011</td>
</tr>
<tr>
<td>26 participants</td>
<td>21 participants</td>
</tr>
<tr>
<td>HIVoices 2</td>
<td></td>
</tr>
<tr>
<td>May 06-08, 2011</td>
<td></td>
</tr>
<tr>
<td>20 participants</td>
<td></td>
</tr>
<tr>
<td>HIVoices 3</td>
<td>Total: 66 HIV+ MSM</td>
</tr>
<tr>
<td>September 16-18, 2011</td>
<td>aged between 64 and 24</td>
</tr>
<tr>
<td>20 participants</td>
<td>mainly from North-Centre Italy</td>
</tr>
<tr>
<td>Total: 21 HIV+ MSM</td>
<td>from both HIVoices 1 and 2</td>
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</tbody>
</table>

Total: 66 HIV+ MSM aged between 64 and 24 mainly from North-Centre Italy

Total: 21 HIV+ MSM from both HIVoices 1 and 2
Targets

- Promoting access in HIV+ MSM to some new personal skills and growing tools, helping to implement each other’s own status of well-being and to develop new resources to use against life’s everyday difficulties due to be a gay or bisexual man living with HIV.

How?

- A (individual, pair, little-groups and large-groups) series of structured, half-structured and unstructured learning-by-doing activities, with a combination of bodily, verbal and emotional languages, helping participants to actively take part and both cognitively and emotively activate their selves.
Detailed targets

- Encouraging to socialise and share personal experiences in a belonging to a HIV+ MSM peer-group context.
- Implementing identity integration and self-acceptance as HIV+ MSM.
- Experiencing the trust process building as base of the relationship with the Other.
- Deepening LGBTQ cognitive contents to promote personal growth.
- Experiencing self-knowledge, in three dimensions of: doing, thinking and feeling.
- Providing cognitive and emotional tools to manage the ‘telling/not-telling’ matter.
- Providing tools for better understanding of one’s erotic-affective dynamics as HIV+ MSM.
- Encouraging to share about differences in everyday life to be dealt with.
- Helping to share and use community building tools.
Workshop topics

*HIVoices* and *Sono Sieropositivo* propose the following topics:

• Belonging, difference and self-perception in the peer-group relationship
• Identity awareness, self-acceptance and esteem
• Identity stereotypes, psychological projection and assertiveness as HIV+ MSM
• Connections between HIV status, gender identity and sexual orientation
• Personal history and sharing of personal experiences
• Emotional and bodily awareness
• Discrimination and HIV
• The body, sexuality and affectivity awareness
• Peculiarities in sexual and love dynamics between HIV+ MSM
Methods

- A non-formal group education methodological approach is used, based on non-steering, experimental and learning-by-doing concepts.
- Working always on the ‘here-and-now’ group-object dimension, never on one subject and his past personal experience.
- The group doesn’t have a common goal. Each participant learns differently, according to personal and collective resources to exchange information, listening mutually to each other, respecting each other’s timing and limits and experimenting with different ways of cohabitation.
- The group is stimulated by the trainer to achieve a new cognitive and emotional consciousness, without any revision or interpretation of participant’s personal past-lived. The trainer is a tool, that the group decide how, when and even if to use.
Methodological keywords

- The **Here-and Now** dimension
- A new **group** culture
- The **peer** concept
- The **Otherness**
- The **relationship** with the Other
- The **non-virtual** environment
- The **experience based** workshop
- The **protected** environment
- The **residential** environment
- The **well-being**
## Results

<table>
<thead>
<tr>
<th>1) PARTICIPANTS APPROVAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A)</strong> Final evaluation forms</td>
</tr>
<tr>
<td><strong>B)</strong> Community building tools use</td>
</tr>
<tr>
<td><strong>C)</strong> Increasing request for applications</td>
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</tbody>
</table>
| **D)** Acceptance to other Cassero Salute proposals | - Interviews  
- Social research  
- HIV related events  
- Second level workshop |

<table>
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<tr>
<th>2) PARTICIPANTS EMPOWERMENT</th>
</tr>
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<tbody>
<tr>
<td><strong>E)</strong> Final evaluation forms</td>
</tr>
<tr>
<td><strong>F)</strong> Sono Sierositivo participants personal growth and evolution</td>
</tr>
</tbody>
</table>
HIVoices 1+2+3 final evaluation forms data (1 to 10 rating scales)

<table>
<thead>
<tr>
<th>IN THIS WORKSHOP...</th>
<th>Median score</th>
<th>Tot. valid answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I acquired tools to increase my self-esteem.</td>
<td>7.51</td>
<td>66</td>
</tr>
<tr>
<td>2. I acquired tools to live better with my HIV status.</td>
<td>7.79</td>
<td>66</td>
</tr>
<tr>
<td>3. I acquired tools to live better with my sexual orientation.</td>
<td>7.47</td>
<td>64</td>
</tr>
<tr>
<td>4. I acquired tools to relate in a different way with myself as a HIV person.</td>
<td>8.15</td>
<td>66</td>
</tr>
<tr>
<td>5. I acquired tools to better understand my emotions.</td>
<td>8.10</td>
<td>65</td>
</tr>
<tr>
<td>6. I acquired tools to better understand the relation I have with my body.</td>
<td>7.40</td>
<td>66</td>
</tr>
<tr>
<td>7. I experienced new ways to be connected and to share with similar people, all of us being HIV+ MSM.</td>
<td>8.93</td>
<td>66</td>
</tr>
<tr>
<td>8. I increased my ability to recognize my own fears due to my HIV status.</td>
<td>8.67</td>
<td>66</td>
</tr>
<tr>
<td>9. I found similarities between my own homosexuality and HIV status acceptance paths.</td>
<td>7.62</td>
<td>65</td>
</tr>
<tr>
<td>10. The workshop enriched me.</td>
<td>9.14</td>
<td>64</td>
</tr>
</tbody>
</table>
Conclusions

• Confirmed a parallelism between internalized homophobia and a similar concept of HIV, that could be called internalized HIVphobia.

• This concept, indeed still poorly investigated, is certainly connected in HIV+ MSM to the homophobia concept (both internalized and hetero-directed).
Internalized HIVphobia (1.2)

- Ensemble of negative meanings connected to HIV virus that each HIV+ person has built during his/her own entire lifetime and has not cognitively revised.

- It is unconscious and deeply settled, it may occur in different forms of uneasiness (anxiety, fears, guiltiness, personal devaluation) and closure behaviours (isolation, social invisibility) acted by people living with HIV against themselves.
Internalized HIVphobia (2.2)

- During workshops it has emerged that participants are able to recognize more easily their own internalized HIVphobia rather than internalized homophobia.

- Because, as a participant said: *HIV is a disease, while homosexuality is a beautiful part of my identity* (A.)
Future prospects (2012)

The training path is continuous, both in a quantitative and a qualitative way, according to 3 directives:

1) to keep on offering new editions of HIVOICES to new-participants;
2) to re-offer new editions of Sono Sieropositivo to the first level workshop participants;
3) to offer a completely new third level workshop to both first and second level workshops participants.
II

A Social Research Involving the Participants of the Workshop HIVOICES
Background (1.2)

Little is known, in Italy, about how HIV+ MSM live and what they think:
• No relevant social research; only clinical, epidemiological (quantity, risks), personal, mass-mediatic, anectodal data.
• The scientific, gay, HIV+ communities don’t know them (as a group).
Background (2.2)

The value of HIVOICES can be strengthened also in terms of scientific enquiry:

• It can get in touch with a number of people who are scattered and otherwise invisible;

• The sample made up of its network, albeit of limited size, offers the opportunity to study a number of issues otherwise impossible to deal with.
A social research has been carried out involving HIVOICES participants.

**Issues:**
- Impact of HIV on own life. Well-being, health services and professionals, treatments. Social and sexual life. Coming out
- Behaviours, opinions, attitudes
- Past, present, future

**Key-words:**
- Approach: monographic, applied, bio-psycho-social
- Representativeness?
# Methods

Qualitative and Quantitative.

<table>
<thead>
<tr>
<th><strong>Recruitment</strong></th>
<th>Invited by the project manager (privacy)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tools and times</strong></td>
<td>- Semi-structured face-to-face interviews (aug 2011)</td>
</tr>
<tr>
<td></td>
<td>- On-line questionnaire (sept 2011)</td>
</tr>
</tbody>
</table>
Sample

Interviews:
• 12 HIV+ MSM; were also invited to fill in the questionnaire

Questionnaire:
• 50 HIV+ MSM (out of 66 participants, 75.8%)
• Age: 25-64, mean: 42.9 (3 generations)
• Know they are HIV+: for 1 to 25 yrs
• 38 are on treatment, 12 are not
• Northern and Central Italy
• Different relational statutes
Preliminary results

From the quantitative sample:

- *Perceived own mean of transmission*
- *Personal visibility*
- *Experiences of rejection*
- *Opinions towards anti-HIV drugs and treatments*
- *Opinions towards nowadays discussed issues*
Perceived own mean of transmission (% to 100)

- UAI: 67.3%
- Oral sex: 18.4%
- Other sex with M: 6.1%
- IDU: 2.0%
- Don't know: 6.1%
Visibility as gay and as HIV+ (index 0-10)
Experiences of rejection as HIV+ (% of yes)

- Dentist: 6.8%
- Occasional partner: 62.1%
- Stable partner: 37.1%
Fears towards anti-HIV drugs (% of yes)

- In general
- As reminders of the infection
- Being recognized during taking
- Commitment to compliance
- Short-term neg side-effects
- Long-term neg side-effects

- Now, on treatment
- At the beginning, on treatment
- Not on treatment
Opinions towards nowadays discussed issues (% to 100) 1.2

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-infection is a real risk</td>
<td>85,4</td>
<td>12,5</td>
<td>2,1</td>
</tr>
<tr>
<td>Re-infection is a risk I am always aware of</td>
<td>64,6</td>
<td>33,3</td>
<td>2,1</td>
</tr>
<tr>
<td>&quot;Swiss Statement&quot;</td>
<td>8,3</td>
<td>89,6</td>
<td>2,1</td>
</tr>
<tr>
<td>Early start of the treatment</td>
<td>53,2</td>
<td>21,3</td>
<td>25,5</td>
</tr>
<tr>
<td>Anti-HIV treatment for HIV-people w. many partners</td>
<td>8,3</td>
<td>83,4</td>
<td>8,3</td>
</tr>
</tbody>
</table>
Opinions towards nowadays discussed issues (% to 100) 2.2

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>In 5 yrs: vaccine for HIV-</td>
<td>27,1</td>
<td>56,2</td>
<td>16,7</td>
</tr>
<tr>
<td>In 10 yrs: vaccine for HIV-</td>
<td>68,8</td>
<td>20,8</td>
<td>10,4</td>
</tr>
<tr>
<td>In 5 yrs: cure for HIV+</td>
<td>18,8</td>
<td>66,6</td>
<td>14,6</td>
</tr>
<tr>
<td>In 10 yrs: cure for HIV+</td>
<td>48,9</td>
<td>32,0</td>
<td>19,1</td>
</tr>
</tbody>
</table>
Preliminary conclusions

• Mixed population; invisible, rather optimistic, cautious about new challenging proposals
• Relevant differences of opinions towards anti-HIV drugs. Something missing?
Thank you for your attention!

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