Discrimination and strength – A photovoice project with immigrants living with HIV in Germany

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Overview

• Deutsche AIDS-Hilfe e.V. (DAH)

• Immigrants and HIV/AIDS in Germany

• Stigma Index Study

• AfroLebenVoice Project

  ➢ PhotoVoice Training and Implementation

  ➢ Examples from AfroLebenVoice/Products

  ➢ Conclusion & Discussion
National association of 127 AIDS service organizations (ASO)

Non Governmental Organization

Focussing on self-help and HIV prevention with vulnerable populations (MSM, IDU, CSW, immigrants, prisoners)

Structural approach to HIV prevention: social context, empowerment, community participation
Immigrants and HIV in Germany

Population with migration background

~18% of the general population in Germany

High heterogeneity within group due to:

- country of origin
- legal status
- migration experience
- socioeconomic status

HIV-positive immigrants

~ 30% of new HIV diagnosis in Germany

Vulnerable immigrant groups further differ by:

- HIV risks
- access to health care
Experiences of stigma and discrimination of People living with HIV (PLWH) in Germany

<table>
<thead>
<tr>
<th>Germany</th>
<th>Immigrants</th>
<th>Non – Immigrants</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusion from a social gathering</td>
<td>21,5%</td>
<td>9,6%</td>
<td>0,1%</td>
</tr>
<tr>
<td>Exclusion from family activities</td>
<td>19,9%</td>
<td>9,8%</td>
<td>0,1%</td>
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<tr>
<td>Gossiping</td>
<td>67,3%</td>
<td>51,1%</td>
<td>0,1%</td>
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<tr>
<td>Sexual rejection</td>
<td>57,4%</td>
<td>43,8%</td>
<td>0,1%</td>
</tr>
<tr>
<td>Denial of health services</td>
<td><strong>32,9%</strong></td>
<td>15,0%</td>
<td>0,1%</td>
</tr>
</tbody>
</table>
AfroLebenVoice – a photovoice project

Partners: Deutsche AIDS-Hilfe e.V. (the national AIDS service organization), AfroLeben+ (a national self-help group of immigrants living with HIV in Germany), Prof. Hella von Unger

Project duration: 2012 - 2013

Community-Based Participatory Research / Photovoice

Project aims: to explore the social impacts of stigmatization and discrimination of immigrants living with HIV in Germany and to evoke action for change
AfroLeben+ is a national Self-Help Group of HIV positive, primarily African immigrants which was founded in 2001.

AfroLeben+ Members act as regional contact persons for immigrants living with HIV in Germany.

AfroLeben+ Members offer support on topics related to living with HIV in Germany, do prevention work in their communities and initiate regional Self-Help Groups.

AfroLeben+ meets four times a year. The meetings are funded by the Deutsche AIDS-Hilfe e.V.
Photovoice as a participatory method of community-based research (CBR)

“Photovoice is a process by which people can identify, represent and enhance their community through a specific photographic technique. It entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own communities.” (Wang & Burris, 1997: 369)
AfroLebenVoice - Procedure

Planing → Trainings → Field phase → Discussion → Analysis → Products → Evaluation

Jan 2012 → Dec 2013
Participatory Project Planning (2 Workshops - 1,5 days each)

- Project aims
- Timeline
- Budget (cameras, appropriate fees to participants for their time and efforts in collaboration, printing costs, board and lodging, products, translation etc.)

Who takes part? (informed consent)

Sixteen members of the Network AfroLeben+ chose to take part in a photovoice project
AfroLebenVoice - Training

Training (2 Modules - 1.5 days each)

Introduction to photovoice
What can we take a photo of – and how?
Clarify the role of the participants
Consider ethics(*) and data protection aspects:
Photos of persons only with their agreement
Caution with photos of vulnerable persons (people living with HIV), sensitive topics and criminal/criminalised activities

(*) Principles of research ethics: AfroLebenVoice participants must be familiar with process of informed consent, data must be treated confidentially (anonymized)
AfroLebenVoice – Field Phase

Field Phase (4 Workshops – 1,5 days each)

Questions that guide the participants include:
1) What makes you feel sad in Germany?
2) What gives you power in life?
Participants present their photos: What do you see here? (description of the contents); Why did you take this picture? How does this relate to your life? (context)

The group discusses the photos

Main issues and results are summarized

The assignment for the next field phase is defined

The cycle (field phase - discussion - field phase) is going to be repeated until the topics repeat resp. the main topics are discussed
AfroLebenVoice – Field Phase

Further steps:
- Writing the stories
- Recording the stories (digital stories)
A few examples of the diverse information collected by using photovoice

Example “What gives you life power?”

Ama: “I moved to Germany in 2007, shortly afterwards I was tested and when the results came back, I was HIV positive... In Africa this diagnosis is considered as ‘a visa to the cemetery’. I decided to draw back and to wait for death. It didn’t come. Thanks for the good medical care in Germany I started to feel much better very soon... I got in contact with the local Aids-Service-Organisation which helped me to meet other HIV positive people and share my experience with them. Many of these people told me that they have been living very long with this disease... Thereby they reawakened my will to live and the hope that all my wishes will come true.”
A few examples of the diverse information collected by using photovoice

Example “What gives you life power?”

Kalinga: “I have to mention two points which are very important for me and are giving me energy to live – one of them is the German Social System. The human being is one who always complains (especially the German beings) – dissatisfaction when one gets everything on the table, people find always something to complain about – wants a bit more here and there! I'm talking about the German Social System which gave me the chance to have a very complicated but very good health insurance! This System is the reason why I'm standing here today with a lot of power and glory... good medication and good doctors.

I have got the ability to have beautiful healthy children despite my disease – what can be more beautiful than that? I do not know where I would be today if I did not come to this country, perhaps dead...? You never know!!!”
Peer-based Analysis:

1. Choosing photos (Which photos are relevant and show not only key forms of discrimination experienced by the participants but also their coping strategies and strengths)
2. Contextualization (storytelling)
3. Codification (identify main issues/themes)

- Development of recommendations
Experiences of stigma and discrimination in Germany:

- German laws & institutions – (no access to work, medical care and treatment, education services etc.)
- Medical sector (doctors, nurses etc.)
- Family, community
- Mass media (campaigns)
- Internalized stigma and fears
AfroLebenVoice – Recommendations

• Politics: protecting the human rights of refugees and other immigrants, overcoming legal discrimination (restricted access to health-care system, restrictions of mobility due to residency obligation etc.)

• Medical sector: offering intercultural trainings, further education related to hiv treatment and care, multilingual services etc.

• Preventive practice - using positive and inclusive pictures of immigrants, (avoiding cliches and stereotypes), enabling participation of immigrants in HIV prevention, supporting self-help groups etc.

• Mass media – more balanced and differentiated reporting

• Communities - providing appropriate information on HIV and living with HIV
• Photo Catalogue
• Mobile Exhibition
• Web-Site (Images und Digital Voices)
• Publications
• New Project Ideas
Diese Stigmatisierung von Afrikanern – das machtKomplexe, das deprimiert.


Prävention ist auch anders möglich!

Das alles entwickelt sich weiter, und es gibt nicht nur negative Kampagnen wie z.B. die derzeitige Antiretroviral-Therapie (ART) von BPA. Die Debatte um die Wirksamkeit der ART, ihre Risiken und die Kosten, die Prävention noch immer möglich ist ohne Stigmatisierung von HIV-positiven Menschen – Menschen. Mein ganzes Denken ist, dass diese Entwicklung sich durchsetzt!
Zwei Punkte sind sehr wichtig für mich. Sie geben mir Kraft und machen mich glücklich: das deutsche Sozialsystem und die Meinungsfreiheit.

Das deutsche Sozialsystem

Der Mensch ist ein Wesen, das sich ständig erinnert [besonders deutsche Menschen], Unzufriedenheit, obwohl man alles auf den Tisch bekommen. Man findet immer etwas zu morden, will sich blicken, nehmlich hier und ein buchten mehr dort.

Impact of the Research

„AfroLebenVoice is not a project, it is my medicine“

„I am not alone!“

„I am relieved!“

„I know more about my rights here in Germany. I have learnt to say „yes“ or „no“."

„I am a person without papers... I don`t have any rights here... But I was needed for this project – which makes a difference.“

„I thought that my problems are only my problems... but here I have learnt that my sisters and brothers have similar problems...which means that other immigrants in Germany have the similar problems. So, I want my story to be used in order to help my sisters and brothers outside.“
The process of taking pictures and telling stories helped participants to reflect on their personal and community experience with stigmatisation as immigrant PWHL in Germany.

It helped to create a critical dialogue and to share knowledge about personal and community-coping strategies and desired change.

The use of photovoice allows the creation of alternative and inclusive knowledge.

It enables community members to participate in a variety of ways regardless of different abilities such as literacy level or language.

It enables communities to create campaigns which are more accessible, inclusive and address people on many levels.
“… no-one is hard to reach, just more expensive to reach.“
(Wilson, 2001)

Thank you!!!