

AfroLebenVoice

our voices against discrimination

a photovoice project with HIV-positive immigrants



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Tanja Gangarova, Prof. Dr. Hella von Unger

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At the request of the project participants, all stories and persons are kept anonymous in order to avoid potential risks for them – in particular regarding their HIV status and the associated social stigma.

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Photovoice – Giving photos a voice, making photos tell a story, using photos to visualise personal stories, using photos to give people a voice.

Eighteen brave people from the Afro-Leben plus network participated in AfroLebenVoice, one of the first photovoice projects in Germany, and the first one to deal with HIV. With great enthusiasm and hope for change, they created open-minded pictures, took photos and shared their very personal stories, some of which leave you speechless or make you sad, while others are positive and encouraging. They creatively expressed their experiences in an entirely unique and personal manner, and jointly developed options for action.

Dear readers, please find a selection of these photos and stories in this book. They demonstrate that the photovoice method has the power to give a voice to people who would otherwise not be heard. It makes it possible to experience life stories and enables dialogue, communication and understanding.

Our sincere thanks go to all those who embodied and shaped this project – for their openness, creativity and great commitment, for sharing their realities of life and world views and for making their voices heard.

Many thanks to Tanja Gangarova, who initiated, co-created and coordinated AfroLebenVoice on behalf of Deutsche AIDS-Hilfe, and to Dr. Hella von Unger for her scientific support.

Now it is up to all of us to stand up against discrimination in all its forms and to enable immigrants in Germany to live a life with equal opportunities.

Silke Klumb

Executive Director of Deutsche AIDS-Hilfe e. V.

introduction

As part of the AfroLebenVoice project, members of Afro-Leben plus, the network of HIV-positive immigrants in Germany, as well as scientists and workers of Deutsche AIDS-Hilfe (DAH, German Health Service Organisation) collaborated as equal partners between 2011 and 2013.

The core component of our project was the participatory and creative method called photovoice. The name incorporates the word “voice” to express the method’s purpose. The idea behind it is that people from groups like Afro-Leben plus, who so far have hardly had the chance to speak out for themselves, find a voice and make themselves heard.

Basically, photovoice works as follows: People take photos of their living environments, share their stories “behind” the photos and figure out together what they have in common and what needs to be changed.

In this particular case, the members of Afro-Leben plus received advisory, methodological and financial support from service providers and scientists in capturing and reflecting on their experiences with (multiple) stigmatisation and discrimination in Germany. Their photos and stories answer two questions: What makes you sad in Germany? And what

are your sources of strength? This second question was also important to us so as not to focus only on negative aspects.

AfroLebenVoice was aimed at initiating change processes:

- *Internal:* We attached great importance to enabling a respectful and constructive dialogue about discrimination and sources of strength. We wanted to activate and strengthen the resources, skills and knowledge of the participants.

- *External:* We wanted to use the project results to raise public awareness of the participants’ reality of life, thereby contributing to eliminating discrimination against immigrants in Germany.

The application of the art-based photovoice method also enabled people to participate in the project who have difficulties expressing themselves in writing or verbally, for example because of language or emotional barriers. Sometimes it only took a little bit of support, sometimes it was enough to hear the stories of others for something like a chain reaction to be triggered among the participants: Statements such as “That could be my story” motivated others to join. For me, as the project coordinator, this was an overwhelming experience

– and enabled us, service providers and scientists, to acquire knowledge that would otherwise not have been accessible to us.

This photo book presents a small selection of the photos and stories compiled as part of AfroLebenVoice. It is the product of the participants’ creative and political analysis of their reality of life in Germany. Many stories gave rise to political demands, which we have compiled at the end of the photo book. Further stories will be published elsewhere, for example as part of a mobile exhibition, in the form of a calendar and on the Internet.

My sincere thanks go to all involved in AfroLebenVoice – especially those who share their life stories with us in this book. Unfortunately, I cannot mention them by name: At the request of the participants, we have jointly decided to keep the stories and persons anonymous in order to avoid potential risks for them – in particular regarding their HIV status and the associated social stigma.

We hope and wish that this photo book will inspire reflection, discussion and action.

Tanja Gangarova
Migration Consultant of Deutsche AIDS-Hilfe e. V.
& Project Coordinator

Tanja: The magic word is “surfboards”

This photo book is based on the connection between visual presentation and stories. Its implementation is the result of a long creative and emotional process, which also had an influence on me, as the project coordinator. So let me start with a little story, too:

I remember very well the day we discussed the topic of “recognising changes in life as opportunities” with immigrants from the Afro-Leben plus network. The attending therapist explained to us by means of a picture that every change in life – also the immigration process – comes in the form of a wave. A wave that brings along a great deal of energy. She said the trick is to recognise this wave as an opportunity and to learn how to ride it. If we fail to do so, we will be buried by the wave.

A nice way of putting it – I thought to myself. At that point, a participant interjected: “There’s something missing! In order to be able to ride the wave here in Germany, we need surfboards, which we usually don’t have.” Indeed, the magic word is “surfboards”!

I am telling you this story because it reflects the reality of many immigrants in Germany. People who have no equal access to medical care, the labour market and education and are additionally excluded from social life, cannot start surfing in the first place – even if they bring the corresponding skills and motivation with them. The structural and social prerequisites – namely the surfboards – are missing.

We started AfroLebenVoice against this background to enable people to participate who have so far hardly been heard. Their photos and stories are the expression of a creative and political analysis of their reality as immigrants and HIV-positive people in Germany. They give a clear account of the areas where “surfboards” are required to counteract isolation processes and to make it possible for all to “ride the wave” on an equal footing.



Pete: I've always been dreaming of freedom

I come from a country where human rights are not respected and I was raised in a culture dominated by men. I've always been dreaming of more personal rights for myself, of freedom ...

After many sad things had happened to my family and me, I had to flee to Europe. That's how I ended up in Germany. I applied for asylum and had to go to the "central reception facility" at the asylum-seekers' hostel, where I was accommodated in a room with three other women. We had one toilet and one shower for the whole storey. There was also a common kitchen, which we were not allowed to use.

We got a meal three times a day in a "dining hall". The "dining hall" was supervised by two guards. Before and after meals, we had to wait in a long queue. Before meals, we waited to get our food, and after meals ...

We were not allowed to take food to our rooms; it was strictly prohibited. They told us for reasons of hygiene, to keep cockroaches out of the room. So, after meals, we had to wait again in a queue for the guards to search us for food. We had to show the content of our bags and pockets to the guards, stretch out our hands to show they were empty, and sometimes we were searched even more closely to find out if we were hiding food. Children had to undergo the same procedure. After every search, I was wondering if I was still a free individual or had already become a cockroach myself.



Pete: I can't eat apples anymore

I come from a country where there are hardly any apple trees, so poor people can't afford apples. I always dreamt of big, juicy apples ... until – because of traumatic events – I had to flee to Germany and ended up in a reception facility for asylum-seekers.

At that time, I was pregnant, I was very weak and had a lot of problems with my stomach. Back then, I didn't yet know of my HIV infection. My condition was getting worse and worse; I could hardly eat anything. My stomach didn't tolerate hot meals; I could only eat few things without having to throw up.

However, we only got food the government had selected for us. It also included big, juicy apples – just like those in my old dreams. We got these apples again and again ... as the only kind of fruit. We got an apple every day, except for Sundays – when we each got two. This went on for months ...

As I was pregnant, I once asked if I could get a banana or a pear for a change, but this wasn't permitted.

Today, my residence status is better, although still somewhat uncertain, and now I can afford apples. But I can't eat them anymore – they always leave a bitter taste in my mouth.



Theresa: The way the doctor told me was unbelievable!

After several weeks of diarrhoea, I was hospitalised in 1995. I underwent a lot of examinations and was asked if I wanted to take an HIV test. I thought about it for a long time and discussed it with my African friend. He asked me, “Are you ready for that?” and I said, “Yes, I am.” I took the test and was discharged a week later – with a doctor’s letter for my GP. I thought it was meant for the doctor, so I didn’t open it.

Then I went to see the doctor. I didn’t know him very well, because I had only seen him once when he had referred me to the hospital. I went in and gave him the letter. He opened and said, “You have AIDS! Here’s an address you can refer to.” That was it.

The way the doctor told me was unbelievable! At first, I got light-headed and thought: So many millions of people have already died of it ... I almost passed out, and he only told me to please go to the waiting room. I came out with tears in my eyes. I couldn’t think anymore. The waiting room was empty. The doctor walked around and I was just sitting there. He didn’t say anything at all. I’m still thinking of visiting him again and telling him what he had done to me.

I ran home in complete panic. Jesus, I’m dead, I thought. I came home and saw my daughter – she was seven at that time – and started crying, because I thought it was the end and we were completely alone in Europe. What was I going to do?



Theresa: I feel good!

Thank God, the address of the specialist HIV practice my GP had given to me was helpful. I went there and the doctor said to me, “Hello, how are you? Are you okay? What’s up? Come on, relax!” I told him that I was ill and that I was going to die soon. He laughed and said, “Just live your life!” It was the first doctor who encouraged me, he also spoke English. He recommended that I go to a self-help group for women, where I had a fresh start. I stayed with this doctor for a very long time. Now I have another one, who is even better. I feel good!

Then I met my husband. He is HIV-negative, black and accepts me with my infection. When I met him for the first time, I was completely alone. As a woman, you reach a certain point in your life as you get older, when you no longer want to keep dating different people, but seek something that lasts. Not because you want to have children (I’ve already got one), just to “settle down”.

When I told my husband that I was positive, he just said, “I’m marrying you, not your positive status!” At first, I thought he was playing games to get me into bed and I said to him, “I don’t want just a one-night stand; I’m looking for a husband.”

“I’m your man and I want to marry you!”, he said. This happened the night when we first met. That’s not how it usually goes ... We are still happy together and it still feels like a dream!



Blessed: I couldn't think of anything but death

I was working and looking after my children in Uganda. In June 1991, I came down with fever, cough and skin rash. I decided to take an HIV test, because many people died at that time.

The test result was positive. It was a shock for me, I couldn't think of anything but death. I told all my relatives that I was going to die of AIDS. This had the consequence that my children and I were stigmatised and discriminated against. I packed our bags and moved with my children to the countryside, because I thought I was going to die soon.

My children suffered very much from no longer living in the city. They had to go to a village school for a long time, because I lost my job and was preparing to die. But death didn't come. After some time, I took another HIV test. It was positive, too, but this time I wanted to know everything about HIV and about my life expectancy.

I returned to the city and joined the "Philly Lutaaya Initiative", a group of people who wanted to make their experiences public. This group achieved a great deal, because it touched people and motivated them to get tested, and people with an existing infection were strengthened through our experiences. These activities helped me become stronger and accept myself. I attended many seminars and workshops, and learnt how to live a positive life with the virus.

I've also encountered discrimination in Europe, and even here in Germany. Some people said, "She is only allowed to stay here because she has AIDS". I feel very offended by that, but I'm afraid to say something. I'm still doing voluntary work. Most of the time, I'm depressed and stressed, but life goes on. And I thank God for still being alive!



Robin: I was called a “filthy pig”

I was born and raised in Africa. This was also where a German family took me in as a foster child. In 2004, we came to Germany together, and I was tested HIV-positive in the same year. The first few years with my German foster family were hell. They treated me like dirt and I was very disappointed by that. I suffered very much from that – and I had no one to talk to.

Later on, I noticed that my passport was gone. I was told that I was no longer allowed to go back to Africa because of my infection. I had to work from early in the morning till late at night. They called me names like “houseboy” and a “filthy pig”. I was told, “You are eating up my pension” and was called a “black monkey” every time I failed to dance to my foster family’s tune.

After I had dared to leave the house two times, they said, “Next time you go out, you needn’t come back. You’ll be all alone and will have to leave Germany without us.”

After my third getaway, I didn’t go back – and I came to realise that there are plenty of good people out there who listen to you and want to help you. Now I enjoy my life, surrounded by good, true friends, people who have the same illness like me. I’m glad to have met such people.

I appreciate that there are establishments like AIDS service organisations and the Afro-Leben plus network. They make it possible for us to meet and talk about our rights and duties. I hope that funding for this network will continue, so that new immigrants can be supported as well.



King Solomon: The compulsory HIV test was a shock

I came to Germany with my wife and my children in 1998 and I always say I was given a second life in that year. Nevertheless, it was a foreign country with a different culture – it was a shock.

The second shock was the compulsory HIV test when I arrived in Bavaria and applied for asylum. There was no counselling, just the test. Two weeks later, at 5 o'clock in the morning, the caretaker knocked on the door of our room at the central asylum-seekers' accommodation. He said to me, "Come with me to see the doctor!"

Several people were sitting in the waiting room, and we were called into the consulting room one by one. The doctor explained to me that I was HIV-positive. It was so tough! I was contemplating suicide, but then I thought of my wife and my children. The doctor took a confirmatory test and gave me the address of the Caritas AIDS counselling centre.

The counselling centre helped me very much. Initially, my wife also supported me. But life at the asylum-seekers' hostel was tough: one room for the four of us, food packages, I was not allowed to work. I went to the unemployment office and said, "I want to work, I don't want charity." Then I found work and life gradually became easier. My children were sent to kindergarten and school. We did a lot together and I helped them with their homework. We had a particularly great time playing football. I gradually became integrated.

But the relationship with my wife deteriorated. She couldn't come to terms with my infection. And then I had to pack my small suitcase again to move out of the flat we shared. I didn't have much when I came to Germany, and had the same small suitcase when I moved out.

Today I live alone, but Afro-Leben plus has become my second family. We are all the same – we are all HIV-positive. The group gives me hope and support. I can talk about everything, because we have a trusting relationship.



Tiko: HIV saved me

Some years ago, I was an asylum-seeker and experienced something terrible. When I went to the foreigners' registration office to have my residence permit extended, I was told without any previous warning, "Your residence permit won't be extended. You have to leave Germany within 14 days. Your flight has been booked." I was shocked: My asylum procedure was not even closed yet, I had a flat, a job (with work permit) and a girlfriend.

I didn't want to go back to Africa. When I had arrived in Germany, I came to know through a compulsory test that I was HIV-positive, and back then there was no medication in my home country.

After this surprising announcement of my deportation, I was immediately taken to court and one hour later to prison, where I was supposed to wait for my deportation. I had no choice but to tell them about my infection, as I was already in therapy and didn't have enough medication with me. I was transferred to a medical ward. After a while, two plainclothes police officers took me to my GP in handcuffs to have my infection confirmed. The nurse had to ask the police officers to remove the handcuffs for the blood test.

With the help of my doctor, my lawyer and the AIDS service organisation, my deportation was prevented. Now I'm allowed to stay in Germany for humanitarian reasons. HIV saved me from deportation.



Ama: He gave me a strong will to live

I came to Germany in 2007; after a short while, I became very ill and sad, because I received this diagnosis ... I just wanted to stay alone in my room and didn't want any contact with other people. I did nothing but cry. And then a German woman got in touch with me and invited me to a brunch at the local AIDS service organisation. I had told this woman many times, "No, I don't want to come. I don't want to hear anything about this disease!" The woman said, "Ama, you can't go on like this and hide forever."

Then I got a letter from the AIDS service organisation with a personal invitation. I thought, "Okay, these people are nice to me. They want to be there for me and visit me at the asylum-seekers' hostel. So why not?" I went there and got to know a lot of people. A German man asked me, "Ama, why are you so calm?" I said, "Because I'm already far away, I've lost all hope." He laughed and said, "Look at me, I've been living with that virus for more than 25 years." "What? 25 years? And you are still alive?" I could hardly believe it, because I thought you couldn't live more than one or two years with it.

Back home, I still thought: 25 years – there is hope! Why am I destroying myself? I should wake up and keep on fighting ... That's why I created this picture, with black and white arms. This man gave me a great deal of strength and hope! Yes, that's nice. He gave me a strong will to live. My condition has stabilised due to good medical care. Now I can make the dreams of my life come true.



Valentin: I would've never survived all this alone

I've been aware of my positive status since 1993. At some point, I stopped wondering from whom, where and when I had got that infection. I've accepted that I'm positive and have learnt to live with it. Back then, the only HIV therapy was the medication Retrovir.

If I had been alone, I would've never survived all this. But I was a single father to a three-year-old son, who always dried my tears and asked me why I was crying. I often sat him in front of the TV to watch "Power Rangers". He asked me, "Daddy, you always say Jesus is going to help us. Can't he help us? Has he forgotten about us? May I say the Lord's Prayer for you?" As soon as he begun, my tears got more intense. He dried my tears. I only said I had heavy pain in my chest.

To take part in a study, I had to travel to the university hospital every day. I had to take the bus at 5 o'clock in the morning and leave my son alone at home all day.

I've refrained from having sexual contacts for twelve years. I didn't want to infect anyone. So I haven't seen women as potential lovers for a very long time. I had forbidden myself to lust after a woman.



Valentin: I'm afraid to tell her

I've been a member of the Afro-Leben plus network since 2003 and also attend the meetings for positive immigrants. At these meetings, I've learnt a lot from doctors, lawyers and social workers – more than from my attending doctor. My hope is growing and I'm learning how to live responsibly with HIV, start a family and have healthy children.

I've learnt that HIV-positive people also have the right to love. The message that successful therapy prevents the transmission of HIV during sex has torn down many barriers.

I've fallen in love with a woman, but I feel bad about it: We love each other, but I can't bring myself to tell her about my HIV infection. I'm afraid to come clean. What happens if she can't deal with it? Is she going to leave me or stay with me? If she leaves me, is she going to keep it to herself or tell all her friends? That would be the end for me, because we have common friends. So I say nothing and I think a separation would be the better solution.

Pete: The most beautiful compliment a mother can get

My picture symbolises the most beautiful compliment I've ever got in my life.

I've always been a loner. Because my childhood was dominated by violence, I've never learnt to trust people and to establish emotional bonds. In addition, I'm lacking self-confidence and have attempted to commit suicide several times. Because of the extreme circumstances and death threats from my family, I had to flee from my country to save my child's and my own life. After a very long and dangerous escape, we arrived in Germany. This is how we became refugees – I'd say scarred by flight and immigration.

My children had to grow up earlier than others to be able to cope with these experiences. The fact that I'm often ill puts additional strain on them. I've always felt guilty for putting too much of a burden on my children. Nevertheless, I always do my best to protect them and allow them to grow up as normally as possible.

I've always been wondering if I'm a good mother and if my children are happy. Some days ago, my son came to me and said, "Mommy, I love you so much, you are the best mother in the world. You are so good to us; if I could, I'd clone you so that other children can have such a great mother, too." This is the most beautiful compliment a mother can get! This is how my lovely children are: They give me the feeling of being needed and loved and, first and foremost, they give me the strength to live on.



Ama: The long wait was out of all reason, pretty lousy on a human level

I'm HIV-positive and come from Africa. Because of a skin problem, my specialist HIV practice had referred me to a dermatologist. We arranged an appointment on the very same day and I was expected to be there at 12 o'clock.

I arrived at the practice half an hour earlier. The nurse at the reception took my referral slip and told me to go to the waiting room. The patients were called in one by one; the time for my appointment elapsed. Even the patients who had arrived after me left and then I was alone. This is why my picture shows the empty waiting room. The nurse, who had the waiting room in her sight the whole time, was already preparing to finish work for the day. Finally, the doctor came. When he saw me, he told me I was supposed to come much earlier. I told him that I had been on time. He took me with him for the examination. Then I was told to make a new appointment with the nurse, but she had already finished work for the day and the computer had been switched off. I was told to come by the next day.

I still don't know why she did this to me. The long wait was unnecessary, out of all reason, pretty lousy on a human level. So why? The skin colour shouldn't matter, although in my city people with a different skin colour still attract attention.

But I'm polite and always try to improve my German skills. The fact that I'm HIV-positive is not my fault. I don't want to be treated differently or worse than others; regrettably, this happens quite often. I call it "discrimination".



Tiko: Happiness through in-vitro fertilisation?

I've been married to my wife for three years. She also comes from Africa, but from a different country than I do, which means that we are culturally very different, but we love each other very much.

My wife's greatest wish is to have a child. She is HIV-negative and is aware of my infection. One day, we heard about the possibility to get pregnant through in-vitro fertilisation and decided to give it a try.

In this procedure, my sperm is washed. The egg is fertilised and the tiny embryo is transferred into the womb. This way, we can get pregnant while avoiding that my wife becomes infected with HIV.

To me, as an African man, the idea of in-vitro fertilisation is weird, but I'd like to fulfil my wife's wish. She takes me the way I am, and the idea of having a healthy child with her gives me much hope. Unfortunately, it hasn't worked so far, but we very much hope it will.

My picture shows a plastic cup – one of those they use to collect my sperm for washing and in-vitro fertilisation.



View: Living at the asylum-seekers' hostel: No discretion, no privacy

Life at the asylum-seekers' hostel is very tough for HIV-positive immigrants for various reasons. Using the common kitchen is unbearable, because many mothers are compelled to seat their children into the sinks instead of the toilet, as there are no toilets for children. There are too few common toilets for the hostel's inhabitants. Two hours after they have been cleaned by the cleaning lady, they are already so dirty again that you can't use them anymore. The men leave their beard trimmings in the washbasin after shaving; nobody bothers to clean up afterwards.

We had a case of tuberculosis at the hostel, which is currently being treated. The hostel staff can enter the rooms at any time, often also accompanied by other inhabitants who need help. There is no privacy.

My mail is often handed over to me by other inhabitants. The letters often bear stamps of relief organisations that fight AIDS, among other things. There is no discretion; I'm always worried about being ostracised because of this.

When shopping with the "food vouchers" we receive from the government, we need to choose the products in such a way that the total price exactly matches the amount printed on the voucher. If the price is higher, the situation becomes embarrassing, because we have to leave the products at the till. If the total amount is lower, you don't get any money back. What do people in the queue think? "One of those asylum-seekers again ..."? I wonder if they suspect that I'm HIV-positive on top.

Despite these difficulties, I'm happy because I receive HIV medication here ... No matter how long the asylum procedure will last, I hope that one day I get my residence permit and thus the right to live a decent life in dignity.



Ngiluri: What makes me feel strong and happy

There are two things that give me strength and make me happy: the German social security system and the freedom of speech.

The German social security system has enabled me to have a very complicated, but excellent health insurance. This system is the reason why I have so much power and strength today. Good medical treatment and capable doctors. I have beautiful, healthy children despite my infection – what more could I want? I don't know where I would be today if I hadn't come to this country. Perhaps dead? You never know!

“No, thanks.” “Not today.” “I don't feel like doing that.”
“Maybe next time.” “I don't like it.” “That wasn't nice.”

Although these sentences are very simple, they are hard to say. But the freedom of saying these words, this freedom of being able to express your opinion without any fear is great, it sets me free. I call it “self-therapy”!

I was raised in a family where it's still a no-no to have an argument or dispute with people who are older than you are. It is unthinkable! No matter how much you want to disagree – tradition and culture don't allow you to do so. They call that “respect”! This respect must be taken as seriously as the daily food, which we don't like to miss!

Here in Germany, I've learnt to say these words – especially to people who are older than I am. But what can you do in Africa? You swallow your words and feelings. That makes you sick! It's nice to let things out – it gives me freedom, it gives me more strength and more joy of life!



Blaise Blay: Suddenly, I saw panic and fear in their eyes

It was on a Sunday when I was hit by a car on a bicycle lane. I was bleeding heavily. When the ambulance car arrived, I was immediately given first aid and taken to hospital. When we arrived, there were as many as four young doctors, who all wanted to help, I could tell by looking at them. So I said to them, “Please put on gloves before touching me. I’m HIV-positive.”

Perhaps I should have known better than to say that: Suddenly, I saw panic and fear in their eyes. A doctor, who was wearing gloves, left the room without saying a word – to get some gloves for the others, I thought. The three remaining doctors looked at each other in panic, then another two of them left the room. The situation became more and more strained, and finally the fourth doctor also left without saying a thing.

The next few hours were the longest in my whole life. They had given up on me; wounded on my head and my legs and bleeding, I was left in the accident and emergency unit. Only because I had reminded them to do their duty. I felt unwanted and useless like a plague.

They gave me enough time to stand up and go away, I could see that in the expression on their faces. I was paralysed, I couldn’t feel anything or move. After two hours and 48 minutes, the department head, a professor, finally came. I had to sign a form saying that I left the hospital on my own responsibility and I took a taxi to get to another hospital, where I had been treated before.

Since that day, I’ve considered very carefully which doctor I see. Doctors are also led by their feelings and don’t always do what’s best for their patients. If even medical staff behave this way, what can you expect from society as an HIV-positive, black immigrant?



Rubi: Two years of mental self-torture

I've been living in Germany for more than 15 years. I applied for asylum. Unfortunately, my application was rejected. The asylum procedure was closed, so I became illegal here all at once. I was in pre-deportation detention two times. As a result of my illegal status, I even had to go to prison. I was in custody for two long years.

In prison, I was tested for HIV without my consent. The result was positive. Consequently, I was kept in solitary confinement. I was told that I was a danger to other people.

I have two years of mental self-torture behind me, being worried and concerned about having to return to my home country. How was I going to live with my HIV infection, how was I going to survive in the first place? I couldn't talk to anyone about it, because I was alone in a cell and had no contact with a social worker or psychologist. I still don't know how I survived it.



Remon: This stigmatisation of Africans – it makes you feel inferior, it's depressing

As early as 20 years ago, there were already plenty of commentaries and programmes that linked African people to HIV and AIDS. It was always the same propaganda: Africa is the main source of these HIV infections, millions of people there have already been infected, Africans have too much sex.

When I hear that, I always think: What? Africans are normal people, just like all others in the world. They have sex like all others and have children. So why are they always stigmatised? Especially when it comes to this subject ... I don't understand that; it gives me strange feelings. This stigmatisation of Africans – it makes you feel inferior, it's depressing.

After my HIV diagnosis, such campaigns are still common. The campaign with the black spider took the biscuit, which is why I chose this subject. To me, the black spider is a symbol of black people.

It's a monster, it's evil and a danger to the white population. Such interpretations occur to me. That made me so said, it hurt me. I felt bad.

It's a shame that prevention still uses such negative images – they spread fear, racism and stigmatisation.

But everything keeps on developing, and now there are also campaigns such as “Positiv zusammen leben” [Living together positively]. They show that prevention is also possible without stigmatising HIV-positive – African – people.

Prevention has ethical and human responsibility. It mustn't be stigmatising and spread fear. In our globalised world, HIV knows no limits; it may affect anyone – irrespective of their skin colour, gender, age or sexual orientation. I very much hope that this development will establish itself.

*Theme of an HIV prevention campaign
from AIDES (www.aides.org), November 2004;
Agency: TBWA\France
Photo: Dimitri Daniloff*



Emily: At this hospital, I wasn't treated like a decent human being

Last year in December, I got hospitalised because of heavy pain in my right shoulder. In the evening, I was surprised to discover that I didn't have access to the bathroom, which was also accessible from the adjacent room. When I asked for the reason, a nurse answered, "You know very well, it's because of your infection!" Another nurse said my neighbour had to be protected. A doctor said that my neighbour had just undergone surgery, and the ward manager told me that she had an exclusive right to the bathroom as a private patient. The next morning, I was at least offered a bowl to "clean myself".

When the pain subsided, I noticed that I didn't get my HIV medication. A nurse told me, "They are so expensive, we can't afford them." I could have been lying there for a week without HIV treatment – a huge risk of resistance development! My relatives then brought me my pills from home.

I couldn't shower for five days. In my desperation, I went to the reception and filled out a complaint form. It didn't take long until I was transferred to a double room with a bathroom to finally have a shower.

My husband and I notified a number of bodies, among them the honorary patient advocate. She told me that I was not allowed to use the bathroom because of my infection. I was completely shocked and came to know that the ward nurse had told her about my infection – an outrageous breach of medical confidentiality!

I had the impression that I wasn't treated like a decent human being at this hospital. If even medical staff treat HIV-positives in such an uninformed and biased manner, what can we expect from the general population?



Keli: HIV is not the end of the line!

When I look back today, I see that my life has never been that of a “normal” person. Although I was raised to “stay on the track”, I often chose to go my own way. I tried to live my life according to my own priorities. The train people jump onto “automatically” – that’s not mine.

When I was diagnosed with HIV in 1996, I thought this was the end of the line. I especially had a problem with the way the subject of HIV and infected people were treated by society. It was like a big finger wagging at me, saying: You did something wrong!

When I told a good friend of mine about my situation, he said to me, “But I have the feeling that you think you did something wrong.” This was the moment when I said to myself: You did nothing wrong, you lived your life just like you wanted to. And the fact that I met the virus on my way shouldn’t be a reason for people to discriminate against me. What I need is solidarity.

Unfortunately, we “positives” experience other people’s fear of the virus. They discriminate against us because they think we are immoral. During the 16 years of being aware of my infection, I’ve learnt many times that this infection is by no means the end of the line, but a fresh start for me to become alert and fight for a society without discrimination and stigma. Even if it’s still a utopia: I’d like to continue being “positive” and believe that it will come true one day! This feeling and my family give me a great deal of strength to keep living this dream!



Lohlian: I mustn't die and let down my family

HIV is a taboo subject. Although some people have already learnt in their home countries what HIV means, there are still many who don't know anything about it. People just don't talk about it. Many people think it's a different disease – HIV doesn't exist. HIV-positive people are often considered immoral by others.

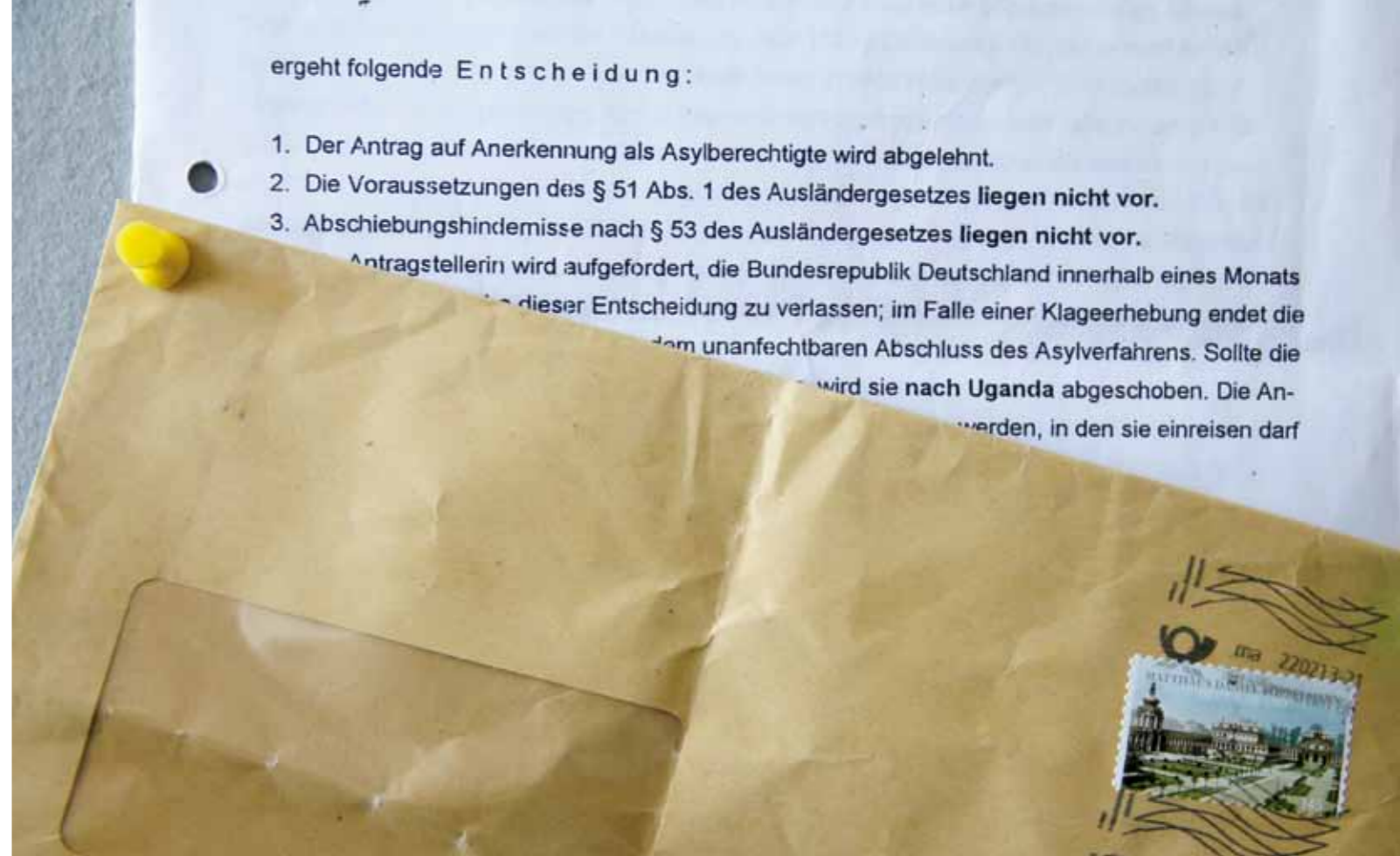
I was told that being ill, for example HIV-positive, would mean being deported from Germany. Therefore, many immigrants are afraid to get tested, even if they suspect an infection. And many of them who are aware of their positive status do not admit it, because they fear deportation or even more discrimination.

For the people at the asylum-seekers' hostel, it was somehow normal that everyone gets a rejection letter from the lawyer or the federal office. For me, this always involved nothing but fear ...

As long as the deportation notice hasn't arrived, there was still hope. But one day I got that notice and only had two weeks to organise my return to Uganda. I was scared. People die in Uganda, even if they take HIV medication, because all medicine combinations are still not available on the market and the treatment is often not adjusted correctly.

Somehow, I yet managed to stay in Germany. Now I take pills every day. But it's hard to find a job here, even if you are not HIV-positive; it's enough to be black and have problems with your residence status.

In Uganda, I have a big family who expect me to support them: I have to pay for their general problems, debts and everything else. So I have to take pills and work, because I mustn't die and let down my family.



Hella: Growing

This is the bark of a plane – a tree you find almost everywhere in Berlin. Planes grow so fast that you can almost watch them grow. The bark is a “scale bark”: It detaches from the trunk in thin plates that look like scales. As a result, planes continuously change their pattern and colour from beige and white-grey to light violet, dark green and brown. When I saw this bark one Sunday afternoon after an AfroLebenVoice meeting, I thought to myself: This is a work of art that is never finished. In a way, the same can be said about AfroLebenVoice. When will it be “finished”? When this book is published?

Photovoice combines photos and stories in a reflexive group process. In our case, the photos were sometimes preceded by the stories, but no matter what came first, the combination of photos, stories and the group process was very powerful. I took part in my capacity as a scientist, I provided methodological advice, moderated from time to time and helped put a story or two into (German) words.

The picture of a dishwasher, for example, was inspired by a story about how a woman had to fight to be respected as a woman and housewife by German members of her family. The discussion made clear: Some participants have had similar experiences. As African women in Germany, they have also experienced prejudice about their technical skills, household organisation and cleanliness. Other photos and stories dealt with public authorities and doctors, compulsory tests and common accommodations.

So as not to focus on only negative aspects, we also asked the participants where they get the strength to cope with all this. In this case, children, faith, hope and love appeared in the photos and stories – in addition to gratitude for being alive as well as the support and assistance provided by other people and establishments of the German health care system and social welfare state.

All these stories detach from the trunk in various colours like the bark of a plane. And there are more stories waiting to be told.



our findings

As part of numerous discussions, members of Afro-Leben plus identified the most important causes and forms of stigmatisation and discrimination against HIV-positive immigrants in Germany by using photos and stories:

The participating immigrants most frequently experience discrimination in connection with laws and institutions – often as part of an asylum procedure or during a “non-registered stay”. This can take various forms: restriction of mobility through the “residence obligation” for asylum-seekers, benefits in kind for refugees in the form of food packages or vouchers instead of free choice, compulsory HIV tests, lack of access to medical care (for example for people who have no documents) or the labour market and many more. Discrimination is mostly related to the attribute of “immigration background” (residence status, skin colour, language, religion, etc.) and, if the person is known to be HIV-positive, also to the HIV-positive status.

Discrimination by medical staff (doctors, nurses, employees in medical practices, etc.) is reported by the project participants as the second most frequent form of discrimination. In these cases, discrimination is assumed to be related to the HIV infection, because the HIV-positive status is known or suspected by the medical staff, depending on the situation. Skin colour is also a frequently reported attribute, and gender can play a role as well.

Stigmatisation is also described as a problem in families and sexual relationships – often after the HIV infection becomes known. Skin colour or immigration background also plays a major role in binational relationships. Gender is also assumed to be a stigmatising attribute (mostly relating to women).

Internalised stigmatisation, i.e. experiencing negative feelings and withdrawal due to fears in connection with the HIV infection is also common. It is often intensified by additional attributes, such as uncertain residence status or skin colour.

Discrimination by mass media and campaigns is described as yet another problem – suspected attributes include skin colour, origin, HIV infection, religion and gender.

Discrimination at the workplace is rarely reported by the participants – which is not surprising, since many of the participants do not have access to the German labour market.

Important: Multiple stigmatisation is reported in nearly all stories. Stigmatisations can add up or intensify each other, but a stigmatisation can also mask another or make it appear less severe – the combinations are multifaceted.

our recommendations

Our recommendations are based on the project results – both positive and negative experiences in Germany – and have been reviewed, specified and complemented by the participating members of Afro-Leben plus as part of several evaluation workshops. The recommendations are addressed to stakeholders who can provide a substantial contribution to eliminating structural discrimination as well as fears and prejudices in connection with (HIV-positive) immigrants – in politics, the media, the medical sector and in preventive practice.

Politics

The human rights of refugees and other immigrants must be protected and the legal disadvantages in Germany must be eliminated:

Equal access to medical care must be ensured for all, irrespective of a person's origin as well as residence and insurance status – also for people who have no documents. Health is a human right and must be accessible to all who live in this country.

Social security benefits for refugees in the form of food vouchers and food packages should be replaced by cash, which the recipients can use at their own discretion. The distribution of food vouchers and food packages is a humiliating, discriminating and thus degrading practice that promotes social exclusion.

The residence obligation during the asylum procedure should be abolished. It is discriminating by restricting mobility and hindering refugees in their daily life. Moreover, it makes it more difficult to get access to adequate medical care: HIV-positive refugees, for example, may only leave the district assigned to them to visit a specialist HIV practice with the permission of the competent foreigners' registration office.

HIV tests without adequate counselling and consent of the respective persons, for example those performed in Bavaria and Saxony as part of the asylum procedure, violate the personal rights of asylum-seekers and cause great damage – also in terms of HIV prevention. They **should be abolished**.

The asylum procedure, which takes years in many cases, **should be simplified and shortened**. It entails an uncertain residence situation and puts additional strain on people who are already in a difficult situation because they live in a foreign country and/or are ill. At the same time, this practice prevents these people from being a part of society.

Immigrants should also be granted unrestricted access to integration courses during the asylum procedure.

The recognition of educational and vocational qualifications should become less bureaucratic. Many skills, educational and vocational qualifications of immigrants are not recognised in Germany, obstructing individual career development and wasting socially relevant resources and skills. The knowledge and skills of immigrants are also important in HIV prevention.

Immigrants must be enabled to take part in all areas of society (educational system, labour market, political decisions, etc.).

Media

Immigrants are often presented in German media in a unilaterally negative way (for example as a strain on or a danger to German society). Media coverage should be more balanced and differentiated, with more positive images of immigrants and preferably with their participation. Cultural diversity should be presented as normal and as a benefit to German society.

Medical sector (medical practices, hospitals, etc.)

Medical staff should be offered training and continuing education regarding HIV-relevant subjects and adequate interaction with HIV-positive people.

The consistent implementation of medical confidentiality and the observance of the right to informational self-determination must be ensured to guarantee anonymity for HIV-positive people.

The intercultural opening of medical services should be furthered – for example, through diversity training courses, inter-/cultural training courses or by using language professionals.

Prevention

Establishments that develop educational material and anti-discrimination campaigns should check their measures and media for the presence of clichés, stereotypes and omissions in the presentation of immigrants. **Prevention and health promotion should use more positive and integrative images of (HIV-positive) immigrants. To this end, immigrants should be involved more strongly.**

German schools should offer more education about HIV/AIDS and about living with HIV in order to eliminate prejudices and fears.

Multilingual and culturally sensitive HIV and AIDS education must be intensified in order to eliminate the stigmatisation of HIV-positive immigrants within their communities.

The range of support services offered to HIV-positive immigrants must be expanded – for example, in the form of self-help groups, networks and meetings for HIV-positive immigrants. These networks provide a valuable contribution to eliminating social isolation. HIV-positive immigrants are strengthened through interaction and support and are enabled to advocate their rights in public and engage in HIV prevention in their communities.

transformations

Words like “liberation”, “power”, “strength” or “courage” can hardly express the participants’ profound experiences. But what is this nearly magical power of this project all about? We have asked all participants about their experiences with the project.

Knowledge/Empowerment

“Now I know more about discrimination and stigma, and I can use this method very well in my work with local immigrants.”

Theresa

“Now I know my rights and can say, ‘This far and no further.’”

King Solomon

“I’ve learnt to say ‘yes’ and ‘no’. Now I can make my own decisions.”

Robin

Strength

“AfroLebenVoice has set me free. I’ve found the courage to tell my little story for the first time, which I had repressed for years.”

Tiko

“Afro-Leben plus and the photovoice project are like a petrol station for me. I go to the petrol station when my tank is empty. So I come here, tank up and can drive again ...”

Ngiluri

“Here I have no fears.”

Lohlian

“AfroLebenVoice has given me a lot of strength.”

King Solomon

“I feel less alone.”

Robin

“AfroLebenVoice is for me not only a project, it is my medicine.”

Ama

From participants to helpers

“I’ve learnt here that discrimination is not only a problem of mine; every one of us here has experienced it. Discrimination also affects other Africans, which is why I want my little story to contribute to other African people, with or without HIV, feeling better.”

Ama

“I used to be an egoist before the project. Now, after having heard and learnt so much, I’d like to do something for others.”

Remon

“I’m only ‘on sufferance’ here and have hardly any rights in Germany. But I was needed [for the project], which makes a big difference!”

Vieux

Trusting the process

“For me, as the project coordinator, it was a great challenge to trust the participatory process – as we, service providers, often tend to want to ‘keep control’ of processes. In this particular case, it was quite easy: Basically, ‘control’ was ensured, because we shared it. At points where the team of coordinators gave up control, the members of Afro-Leben plus took over. This created plenty of space for participation and empowerment.”

Tanja

literature

The photovoice method was developed by Caroline C. Wang and Mary Ann Burris in the 1990s and has since then been widely used, especially in participatory health research.

A good introduction into this subject is provided by

Wang, Caroline C./Burris, Mary Ann:

*Photovoice: Concept, Methodology,
and Use for Participatory Needs Assessment.*

In: Health Education & Behavior 24, 1997, 3: 369–387.

A methodological guide in German is provided by

von Unger, Hella: *Partizipative Forschung.*

Einführung in die Forschungspraxis.

Wiesbaden: Springer VS 2013.