

"Lillian: Facing AIDS, Facing Life"
An African Everywoman with AIDS

Lillian: Facing AIDS, Facing Life tells the story of one woman's battle with AIDS in Uganda. It follows the steps she has taken to improve her life, her daughter's and the lives of others who live in the shadow of the HIV/AIDS epidemic.

Facing the Facts

Imagine that just two months after your first child is born you discover your husband has AIDS. Imagine arriving for his funeral and being met by an angry mob. Imagine then finding out that you too are HIV positive. This is the beginning of Lillian's story. Left alone with her daughter and with her sisters and mother also dependent on her, Lillian must find the courage and means to survive.

Working with AIDS

Lillian coordinates the Uganda Network of AIDS Service Organizations (UNASO) and through her work regains her strength, spirit and zest for life. She provides support for other people living with AIDS and builds a house that will help secure her daughter's future. She runs a joint venture chicken farm which may soon start to yield some profits. Tirelessly, she tries to de-stigmatize AIDS in society and teach those who live with it how to lead a rich and long life.

The Struggle Goes On

The perception of Uganda as one of the success stories in the fight against HIV/AIDS is questioned. How true, in fact, are the statistics provided by the government? Lillian for one does not believe them. She sees opportunities for women, starting with education, as the way to get the country back on track. People like her need to become a part of the decision-making process. But can Lillian carry on performing all of her roles – mother, girlfriend and campaigner –, follow her desire to extend her influence into politics and somehow find the money to pay for the treatment she needs?

The following interview was conducted by Danish author Hanne-Vibeke Holst, UNFPA Goodwill Ambassador and Face to Face Spokesperson. Lillian Mworeko lives in the Kampala suburbs in Uganda and has AIDS.

Hanne:

Were I a cameraman, I would start zooming in on the woman now as she sits slightly slumped in her chair: skin black, hair cropped, hands resting in a wide lap, chunky thighs stretching skirt fabric. I would continue until only her face – fleshy with pitch-black almond-shaped eyes and full, arched lips – filled my lens. The woman's name is Lillian Mworeko, and she is telling me her life story. She speaks softly, almost in a whisper, yet her voice carries clearly through the incessant noises of the African morning: laughter from the kitchen, the hum of an old refrigerator and the chirping of birds in the trees. "Seven years ago," she says, "I was catapulted out of my normal, happy life. It took all my strength to get back on my feet again." What occurred on the set of Lillian's life that day was sadly ordinary – and, in the scheme of things African, even rather banal. Like millions of Africans, Lillian came face-to-face with AIDS. The shock was intense: she had never imagined that AIDS would take center-stage in her life and pass a death sentence on her husband, Alex Mworeko.

Lillian had not been seriously concerned for her husband that morning in December, when she had convinced him to get tested. It was a quick and easy procedure, which could be done at Uganda's blood bank, where Alex worked. And to her, it had seemed merely a precaution. His health had been somewhat poor for a while, actually more than poor. He had had bouts of diarrhea and some fainting spells. Still, she had thought, he probably had malaria or a benign virus of some kind. At a recent check-up, the doctors had just shrugged and sent him home without a clear diagnosis. It was then that the idea of an AIDS test had first come up. Alex was reluctant, though, "What if I really am HIV-positive?" A former girlfriend of his had recently died of AIDS, so he was scared. Lillian, too, had felt a twinge of fear then, but they were newly married, had been blessed with a healthy baby girl (now nearly two months old) and life just seemed too wonderful for anything bad to happen. For the sake of her husband's peace of mind, however, she had nudged him to get it done. And he did on December 21st 1996, a few days before Christmas.

Lillian:

"I waited for him at home with the baby all day. When he finally came home, he walked in empty handed

(usually he brought home fruit and other foods), went straight to our bedroom, and sat down on our bed without saying a single word. I stood frozen to the floor, too afraid to join him, too afraid to ask. His symptoms all of a sudden seemed so obviously AIDS related. Eventually, though, I mustered the courage to join him. Clutching my little daughter, I sat down on the bed next to him. 'Yes, I was tested, and, yup, I sure do have it.' We sat quietly for a while, both at a loss for words. What could we say? I looked at him, at our daughter –it was too overwhelming. We remained quiet for a very long time. 'Well,' I finally said, 'let's figure out what we can do.' But I admit I had no idea how to handle the situation. We lived with my sister then and later with my husband's nephew, and, of course, it was impossible to keep up normal appearances. They knew something was amiss."

Hanne:

At this point in her story, Lillian sits up straight and looks me full in the face. We cut to the present: a morning in her newly built house in Nansana East II, one of Kampala's fringe suburbs. Nansana is so sparsely populated that it almost feels as if we are in the country. The clucking chickens, scraping the brick-red dirt in the back yard; the outdoor privy; and the big water containers, used for hauling water from the village well, definitely add to the country feel.

Lillian's daughter, Barungi, now six years old, joins us and presses her lanky body up against her mother's. She is wearing her prettiest white dress and her hair in little tight bunches. Lillian's neighbor also joined us for a while, offering her quiet support. Without a word, she slid in, seating herself on the edge of a chair, listened to some of Lillian's story, a story she already knew very well, and then she left as suddenly as she had come, gliding out the door like some other-worldly being. I sit blinking back tears, trying to release the tension in my shoulders.

Hanne:

— Didn't you tell anybody that Alex was HIV-positive?

Lillian:

"No, but I think they knew. It was so obvious that he wasn't feeling well. And when he didn't come to my father's funeral, it became clear to everybody that something was seriously wrong. It was an awful time. First my husband gets sick, and then my father suddenly dies. I felt completely at a loss, I didn't know what to do. As the first-born child, I'm obligated to go to my family and take care of the funeral of a parent, but I couldn't very well leave this sick man, my husband. Who would take care of him? I was the only one who knew how to do it properly. In the end, I decided to stay with my husband, postponing my trip home until the day of the funeral. When I got there, I explained that Alex was feeling a little under the weather, but they didn't buy that; my sister had naturally told them how ill he was. And I knew that they were beginning to put two and two together, but, still, I never let on how bad things really were. Instead, I hurried home to Alex, who was much worse. Every day he got a little weaker. And in February he was hospitalized with meningitis. Fortunately they treated him, and he survived, but he was very depressed. Alex was a researcher, as you know, and he studied the illness, and I think that's what finally got to him. Reading about his prospects made him give up, and, really, that's what he did; he simply gave up."

Hanne:

Lillian lets out an almost inaudible sigh. The girl has run off. I take a sip of water, compose myself and make sure the recorder is still working. It is.

Lillian:

"He did have intermittent periods of relative good health when he would go to work. We even bought a car, so he could drive to work. Taking the taxi-busses was too exhausting for him. We never told anybody he had AIDS. We lived with it alone, cocooned in our little world of silence. I wish we had been more open about it – talked to people. Who knows maybe we could have gotten some help. But Alex was adamant; he didn't want to tell anybody, not even towards the end when his health deteriorated dramatically. In April 1998, Alex lapsed into a coma, and I never heard his voice again."

Hanne:

— How were you holding up during his long illness from December 97 to April 98?

Lillian:

“Well, so many things happened and I focused all my energy on this illness. I listened to radio programs and watched TV shows about AIDS. Of course, I was terrified of getting it too; we still slept together, and Alex didn’t use condoms. But I had no symptoms, and hoped I was one of those lucky people that have immunity to the virus. I just didn’t have the heart to ask him to use condoms, and we slept together even when he was very ill. The day he died, I got tested. HIV Positive! I knew I should’ve been more insistent and forced him to use condoms, but you know how hard it is to ask that of someone you love, especially when that person is so sad.”

Hanne:

I nod in assent, as if I could ever know her pain. Her pain is like a soft black veil enveloping every word she speaks in her beautiful English. Of course the difference between her life and mine is spelled A – I – D – S. AIDS is an epidemic raging across her continent for 20 years now. On my continent it is under control. To me it is statistics, to her a painful reality. In Uganda 947,552 have already died of complications from AIDS, more than a million Ugandans currently have AIDS/H.I.V.

Lillian makes a move as if to lift her hand from her lap, but even the tiniest of movements seems to be too strenuous for her at this moment.

Lillian:

“I did try to make him write a will. I’d say things like, ‘Don’t you think, it would be a good idea if you wrote a will?’ But such questions clearly hurt his feelings. ‘Have you given up on me already?’ He’d angrily ask. He thought I was out to get his money, and that I wanted him dead. So I stopped asking. After his death, however, I sorely regretted not having been more resolute. If only he knew what I had to go through because there was no will. His family was all over me after his death, asking if he had left any money. Ironically, they had shown no interest in him while he was ill. They never offered to help me take care of him, not once. And by the time it was over, we had used all our savings to cover the expenses for medicine, the car and so on.”

Hanne:

Talking about the will takes Lillian back to the days immediately before and after Alex’s death. First, she spent two harrowing weeks by his deathbed in the hospital, and then she had to endure a life-threatening encounter with his family at the funeral.

Lillian:

“I remember being so exhausted during those two weeks in the hospital! On the day he died, I was so tired that I kept falling asleep in the chair by his bed. To recharge my batteries, I decided to go for a little walk around the hospital grounds, but during the few minutes I was outside, he died. One of the nurses came running out after me. Oh, it grieved me terribly that I wasn’t there for him when he died. Me, who had stood by him through all his ordeals, failed him in those final moments of his life. I cried and cried and cried. I thought I would never stop crying. But then I realized I had to stop and start thinking about the future. And so I did. I stopped crying and didn’t shed another tear for many months. Even at the funeral my eyes were dry. It was as if all my tears had turned into ice and left me cold, capable and emotionally numb.”

Hanne:

Lillian sucks in air, allowing herself a brief respite, and continues her story in the same tone of voice: soft and subdued. Her inflection tells me that she knows she will get further with prose than poetry, that the heart, after all, is nothing more than a muscle.

Lillian:

“His funeral nearly killed me, literally. I brought my husband’s body home to his parents’ village, as it is the custom here. I arrived late at night in a cab, but the driver cautioned me not to get out. He had the feeling something was wrong. Suddenly throngs of people surrounded us. Some were crying, but most of them were shouting angry words at me, and the air was thick with hatred. ‘Don’t get out now!’ said my driver. I didn’t. We sat in the car for about half an hour, and then drove back the way we had come, stopped, waited

and then returned to the village. Here, we waited again and finally the driver felt it was safe for me to get out. That man saved my life. My in-laws clearly intended to kill me.”

Hanne:

— Why on earth would they want to kill you?

Lillian:

Lillian shrugs. “Well, according to them, I was the one who had infected their son with HIV. In their minds, I was to blame for their son’s death. My father-in-law was so furious he started shouting accusations at me the minute I got out of the cab. I was horror-struck, yet, at the same time, I felt oddly calm and composed, an Ice-Queen.

“You see, all the time he was ill, I had repeatedly asked my in-laws for help. It wasn’t easy to take care of a sick man, a baby and also keep my job. But not once did they offer to help. Not once! But after his death, all of a sudden he was their precious son. I just couldn’t take it seriously, and, I guess, that’s why it didn’t bother me that they were yelling and screaming. Also, I knew in my heart that I had done everything in my power to help Alex. If people don’t recognize your efforts, but blame you for everything, you become hard.”

Hanne:

— You loved him very much, didn’t you?

Lillian:

“Yes, I did. During his illness, we grew closer, and our relationship got stronger. He was such a modest, kind, and understanding man. It seems so unfair that he of all people should get sick, but I guess that’s the way it always is. Perhaps his kindness and modesty explain why his parents thought I infected him and not the other way around.”

Hanne:

— Was it?

Lillian:

“I don’t really know. It’s hard to tell. I mean his ex-girlfriend was sick ...,and although we had both had other partners before we met, neither of us got tested. We weren’t as informed about AIDS then.”

Hanne:

— At the time of the funeral, you knew you were infected. You were an HIV- positive widow with a small child to care for, with in-laws that hated you and were unwilling to help. It seems almost too much for one person to handle. How did you manage?

Lillian:

“Well, it was tough. When I came back to Kampala after the funeral, I almost gave up. I was lonely. I missed my husband. And I thought I was dying. The only thing that kept me going was my daughter. I knew my in-laws wouldn’t take care of her, and my own mother, a widow too, and my sisters were dependent on me as it was. So I steeled myself for a fight and knew it would be hard. With my meager income I had to pay for everything: food, rent, medical bills, transportation etc. But luckily, one day, while I was cleaning up my husband’s things, I found the business card of an Army Major who I knew had AIDS. Alex had briefly worked with him before he got sick, and I had seen him on TV talking about his pioneering work helping people with AIDS to create support groups. So I called him. ‘I’m desperate,’ I exclaimed when I got him on the phone. ‘Don’t be,’ he said. ‘Life goes on as it must.’ Later, when I met him in person, he told me to take comfort in the fact that there were many people out there in my situation. Some are a lot worse off than you. He invited me to one of his workshops, and I was determined to go even though it was at the other end of the country. To my surprise there were nine other young men and women going. From other areas of the country another 40 people came. That is how I got involved in a support group, and became an activist. I probably would have been dead by now, if it hadn’t been for my work as an AIDS activist.”

Hanne:

For the first time during our conversation, a smile appears on Lillian's face. It is like a beam of sunlight breaking through leaden clouds, like the ones blanketing Kampala this morning. Her smile smoothes away all the pain, illness, death and worry from her face. It exudes youth, laughter, hope, love and energy. As she talks about her work, I realize how extraordinary this 37-year-old woman really is.

Lillian:

"When Alex died, I was working for a Catholic Youth Organization that preached sexual abstinence before marriage as the only means to prevent AIDS, which, of course, is completely absurd. Teenagers will have sex regardless of what you tell them. The question is whether they do it with or without a condom. After a while the hypocrisy of their teaching got to me, and I quit. To many of my friends, my decision seemed foolish; after all I was a single mother with several dependents." To UNASO, Uganda Network of AIDS Service Organizations, however, Lillian's decision seemed admirable. Her integrity and courage impressed them and they offered her a job. She started out as a lowly paid trainee but quickly advanced to her current position as the organization's esteemed coordinator.

Hanne:

It is, however, not Lillian's admirable work for UNASO that has informed the choice of her as ambassador for Uganda's women and their fight against AIDS. Rather, the choice was based on her loving personal commitment to the cause as evidenced by all the work she has done for the community where she and her daughter have lived for two years.

— Can you tell me a little bit about how your involvement with AIDS relief has influenced your personal growth?

Lillian:

"Well, as I said earlier, I really crashed after Alex's death. Everything seemed hopeless, and I remained depressed until I started working in this field. Working with AIDS/HIV has changed my life. I've traveled everywhere, worked with a lot of different people with AIDS and in the process I've become a lot more open, stronger and more self-aware. Having a good sense of self is key to understanding and helping others. When you are consumed by your own problems, you can't focus on anybody else – not even your own family.

"Without my work, I wouldn't have had the strength to build this house, for example. The house is crucial for my daughter's welfare if I die young. Her dad left her nothing and his family has refused to acknowledge their obligation to her because there was no will. It is, actually, customary in our culture for the husband's family to take care of the wife and children, make them a part of their clan and provide them with land. I did file a lawsuit on behalf of my daughter, but my brother-in-law, who was summoned three times, never showed up for the preliminary hearings, and I ended up having to drop the charges. I was too exhausted at the time, and it also nearly cost me my job. I had to take a day off from work every time to drive to the district's courthouse, four hours away. Now, however, I'm thinking of reopening the case. Thanks to my job, I have the energy to do it and I feel compelled to do everything I can for my daughter. I want my daughter to know that I'm doing everything in my power to make sure she gets what is legally hers. In Africa, land is everything. If you don't have land, you don't belong; you are nothing."

Hanne:

— Tell me about building the house?

Lillian:

"Well, I tell you, it was quite an ordeal. I scraped and pinched, and let out my car to a taxi driver. Within 12 months, I had saved enough money to buy some land and build this house." Lillian smiles and makes a grand gesture as if trying to encompass the entire house with one sweep of her arm. We are sitting in a large, rather sparsely furnished living room around which echoes every sound we make. "It is not done yet," she continues. "It will be finished slowly but surely. Some day I intend to put in a bathroom and a lavatory. I just haven't been able afford it yet."

Hanne:

— Shortly after you moved here, you organized a local support group?

Lillian:

“Yeah, you see, when I was working on the house, I heard about a man in the neighborhood who was dying of AIDS. Everybody was talking about him. ‘Aha,’ I thought, ‘so that’s what they say about us.’ As soon as we moved here, I looked up the widow and told her about my husband’s death and my own condition. She was shocked. ‘Goodness, you shouldn’t be telling people that you are sick. You are still young; no one will think you’re HIV positive.’ ‘Well, I feel I have to,’ I said. ‘People should know.’ She too was HIV positive, but unlike me, she was ashamed. Consequently, she disliked both my candor and me. Eventually, however, we became friends and spent many hours talking about AIDS and wondering how many of those around us were HIV-positive. Generally they seemed to know very little about the illness, and even less about how to take care of themselves should they ever contract it. I knew, for example, that many people thought AIDS killed immediately. We therefore decided to form a support group. We called a meeting, and a surprising number of people showed up – fourteen women and six men out of a population of a hundred – a mind-boggling number, in fact, that shows you just how bad things really are around here.”

Hanne:

I agreed. The numbers are indeed worrying, and they may explain why some NGO representatives maintain that there is a serious discrepancy between the government’s optimistic numbers and the actual reality of the spread of AIDS/HIV in the country. Uganda is being hailed as a shining example of how the spread of AIDS/HIV can be successfully curbed. It is widely believed that if other African countries such as, for example, Botswana had employed Uganda’s strategy, a staggering 38 percent of its population would not have AIDS/HIV today. The rate in Uganda is stabilized at 6.5 percent of the population (25 million people) according to recently released numbers from its health department, UNAIDS, XXXX, and WHO. Uganda, early on, employed an aggressive multifaceted strategy to slow down the disease that has ravaged the country since the early 80s. Despite the success, however, government officials acknowledge that there are still small geographic pockets across the country where the number of AIDS/HIV cases is significantly higher than the national average, and therefore that it is too soon to stop the campaign. For many, like Lillian and the NGO-representatives who either live or work in these areas, the reality they face every day feeds their suspicions about Uganda’s success story. They see large numbers of sick people all the time; they visit villages where the inhabitants are so far removed from health clinics and the most basic information about the disease that they believe their villages must be cursed. How else, they reason, can it be that masses of people in the prime of life suddenly die? Even here in Nansana, only half an hour’s drive from Parliament, the situation is anything but picturesque. In fact, critics often lament the time politicians spend painting a rosy picture to foreign aid donors of the AIDS/HIV situation in Uganda. Instead, the politicians should spend their time traveling around the country seeing for themselves how bad things really are in places like Nansana.

- Your support group, what has it meant to people here? Has it, in your opinion, made a significant difference in their lives?

Lillian:

“Yes, absolutely. We have educated them on what kinds of help are available. They now know there is free medical care at some clinics in town, that some organizations offer home visitations by doctors and nurses, that you can get treated successfully for many complications from AIDS such as tuberculosis and pneumonia. A lot of people didn’t know prolonging your life with the AntiRetroViral treatments was an option and now that these treatments – once exorbitantly expensive – are more affordable, we strongly encourage people to do everything they can to stay as healthy as possible for as long as possible. I mean, you never know, a medical breakthrough may be just around the corner. If you look at the medical advances within the field of AIDS research thus far, I think there is reason to hope for an imminent cure. The group’s most important function by far, however, is the emotional support we give each other; just knowing there is always someone there for you is invaluable.”

Hanne:

— You have also started a joint venture – a chicken farm, right?

Lillian:

“Yes, we have,” Lillian is all smiles. “It is a small but fast growing farm. We started out with 300 hens and now we have approximately 1500. They are all old enough to lay eggs now and we are hopeful that there will be an adequate enough yield for profit sharing among the members soon. So far, we have been able to provide our members with eggs and the occasional soup-hen, you know, for birthdays and holidays. Would you like to see the farm?”

Hanne:

— Of course, I’d love to. But first, would you mind telling me, who that guy is – the one I’ve seen through the corner of my eye passing like a shadow by your house – is he a brother or a boyfriend?

Lillian giggles shyly like a teenager. “That’s Robert, my boyfriend,” she says and calls him over. Robert is a young, gum chewing dude with a chipped front tooth, a twinkle in his eye and a naughty alley-cat kind of charm. While perching on a chair, he tells me how he met Lillian and what he does for a living. He works as a sales representative for Coca Cola and comes from the same village as Lillian and Alex. “I’ve known them forever,” he explains. “I hooked up with Lillian about three years ago. Actually, we met at a funeral.” “But,” says Lillian with emphasis “we are not living together.” Apparently, Robert visits her now and then, but has his own apartment in town. Curiously, the fact that Lillian is H.I.V positive does not seem to faze Robert who, as far as I know, is not infected.

“A couple of years ago nobody dared touch a person with AIDS. We thought that if you got the virus on a Monday, you’d be dead by Tuesday. But after many years of enlightening AIDS-awareness campaigns, we’ve learned that you can live with someone who has AIDS/H.I.V without contracting the disease. Of course, if Lillian and I wanted a child together, it would be a problem that she is a carrier. It’s possible to prevent mother/child infection these days, but whether there is a way I can be protected, I don’t know.”

— No, I guess condoms aren’t going to work for you in that case, are they?

“You got it,” Robert says laughing. “Condoms aren’t the solution to everything!” Like most Africans, he has lost many friends and relatives to AIDS. (Africa, of course, is not alone in suffering at the hands of the ravaging disease. Globally more than 42 million people are infected with AIDS.) Not surprisingly, Robert is very supportive of Lillian’s work. “In my view, she is a great role model. She travels and does so much for people. They obviously love and trust her. People come to her with their problems, knowing she will do everything in her power to help them.”

I’m given a glimpse of Lillian’s work as we go on a tour of the village. Lillian walks ahead of me holding Robert’s and Barungi’s hands. Our first stop is her neighbor, Betmohanj, a woman on whose property the chicken farm is. As we walk down the little path from Lillian’s yard, we pass a big kid on a bike. He is transporting at least 30 egg cartons on the back of his bike.

“Are those your eggs?” I ask Lillian. She turns to me with a smile of confirmation. While the proud Betmohanj shows me the farm, Lillian, Robert and Barungi run about frolicking in her backyard. Betmohanj is the woman whose husband had just died of AIDS when Lillian moved to Nansana. Like so many here, she grew up on a farm and therefore had some basic knowledge of how to raise chickens. Today, however, she is quite the expert as she has read extensively on the topic. She is well aware that a modern chicken farm ought to have a proper watering system. But money is short, so for now the watering system consists of a couple of bright blue plastic tubs. The chicken feed, leaves the size of elephant ears, are from Lillian’s backyard. She has just harvested an armful of this precious feeding material.

Betmohanj is 40 years old, and, like Lillian, she has AIDS. Unlike her stout healthy looking neighbor, however, Betmohanj is clearly marked by the illness; she has the characteristic deep, dark circles under her eyes that I’ve seen on so many other AIDS patients. Yet, Betmohanj refuses to fall into despair. Despite the frequent occurrence of symptoms, she stubbornly adheres to the group’s mantra of living positively with AIDS, a philosophy that, even though it is a kind of pop slogan among AIDS activists in Uganda, actually seems to work. In short, the thinking goes like this: You need to be open-minded, look after yourself, and hold on to your joie de vivre, good spirits and general humanity if you are to live in peace with your condition. In other words: Don’t worry, be happy!

And in a nutshell, this approach is the survival tactic Lillian is teaching her flock. As Betmohanj, with the all-seeing eyes and the wine-red soft-crowned hat, acknowledges while we’re standing amongst the clucking chickens on the little farm: “Lillian has taught me so much. She is always there for us with advice, she urges everyone to get tested and get treatment. And she is a phenomenal inspiration to all of us. There is no cure

for AIDS, but with the right attitude, you can live a really long time, just look at us.”

Betmohanj’s determination is strong and she will clearly live long. And really, she has no other choice. She is the mother of two adolescents and also takes care of three orphans. The two adolescents are at this very moment eating lunch in the courtyard in the shade of the projecting roof. A radio on full blast pumps out pop-tunes and, intermittently, public announcements like, “Boil your water to avoid cholera.” The three little orphans are children of family and Betmohanj was all they had when their parents died, victims of AIDS.

— So, you have five kids?

The woman nods, hugging one of the kids, who have come up to her. “Yes, I have five kids now.”

[Hanne:] It pains me to hear about the orphaned children. We see many more on our walk through the village. It is estimated that a shocking 1.7 million of Uganda’s children have been orphaned by AIDS, a world record and a ticking time bomb of disaster waiting to explode this already shaky society. Who knows how this substantial group of young, stigmatized outcasts will react when they grow up, probably to become deeply traumatized and frustrated adults.

“Oh, all these orphaned kids, it is so hard to watch them. Each and every day more children join their ranks,” Lillian says as we pass a throng of barefooted toddlers, who have come to stare at the odd-looking foreigners. Mzungi, Mzungi, they hiss as we walk by. ‘Whitesss...Whitesss...’ Some of the younger ones start to cry when our photographer aims his lens at them. “We try to take care of them, of course, but it is a huge obligation, and people have very little energy as it is. Most of us can’t accept more responsibilities than we already have within our own families.”

We are on our way to visit a woman, who is not “feeling well” as Lillian put it. We turn left on the path and come to a house that is more like a hut with the characteristically African sloping roof under which women and children are gathered. They sit chatting on colorful baste mats. As we approach, they greet Lillian with broad smiles.

The woman, we have come to see, is definitely not well. She is emaciated. But while AIDS is her main problem, an immediate concern is an infected abscess on her left temple. The abscess is in itself repulsive, but it isn’t that which makes me take a step back. Rather, it is the mark of death on her bony face that is so shocking. Her feverish eyes have no light; all hope extinguished. Notwithstanding, she tries to put on a brave face, laughing with the other women at Lillian’s little lecture on why there are braided baste-mats in all African homes. “It is because the man, typically seated in a chair, can feel superior to the woman on the mat on the floor. We have them to remind us of our inferiority. Of course, it is no longer like that. Today, we are allowed to sit in chairs,” she concludes as everybody dissolves into laughter.

The laughter quickly dies down, the gravity of their situation never far away. In the quiet, I ask them if they are scared. “Yes, of course we are scared,” they agree. “When you are sick, you constantly worry about your kids...” The woman with the abscess looks away, holding a piece of checkered fabric hoping, to cover it. She lost her first husband in 1990, and her second husband is also infected; there are two children.

[Hanne:] A bare-bottomed little girl, who looks two but probably is three, climbs up on a random lap and starts making funny faces, squeezing her eyes tightly shut as the camera guy points his lens at her. Her hilarious performance brings back the cheerful mood. The little girl is very charming, which may save her life. They tell me she is recently orphaned and dependent on the goodwill of the women in the village. Again silence falls heavy upon us. Instinctively, I understand them. I, too, am a mother and share the universal fear of all mothers: the fear of dying and leaving dependent young children, the most vulnerable beings on earth. Statistically we know that a child whose mother dies before it turns five has a significantly lower chance of making it into adulthood than children whose mothers are alive on their fifth birthday.

We stay and chat with the sick young woman for a while. Lillian talks to her in the local dialect – the woman doesn’t speak English. The photographer buys one of her baste mats that she makes when she is strong enough to work. These braided mats are her only source of income, and she hasn’t been able to make enough to get the abscess treated. Unless treated soon, the infection will spread and eventually kill her.

After we’ve said our goodbyes, Lillian shakes her head with ominous import and says, “It doesn’t look good.” On our way back, we pass the village well, where a group of young men and children are filling containers with water. Some of the more brazen young men come over and jokingly pose for our photographer to the good-natured banter of their friends. When the “models” demand modeling fees, we refuse them point blank to the roaring laughter of their friends. And as we continue towards Lillian’s neighborhood, they hoot good-

naturedly.

In comparison, the houses here are large and roomy, built with hand-made bricks. In the yards, you see piercing-green banana trees and gloriously vibrant pink dahlias.

Hanne:

— Isn't there anything you can do for her?, I ask, trying to find some vestige of hope.

Lillian:

"Well, we've given her medication for her pain and paid her doctor's fees, but we can't afford to buy medicine for any of our members. It is very frustrating because this woman could easily be cured. Instead, she will suffer, and die slowly, long before her time." Making sure Barungi is out of ear shot – she is fluttering about like a white butterfly – I look at the healthy glow on Lillian's face and ask whether she ever has any symptoms.

"Not very often. I have the occasional fever, but so does everybody. My doctor recently told me my immune system is getting weaker and that I should start AntiRetroViral treatments, so I have. I have been feeling a little tired lately and I'm going for a check-up tomorrow. Would you like to come?"

Hanne:

And of course I'd like to come. We make arrangements to pick her up at her house the next day. Just before we leave, I see the fluttering white butterfly and know there is something horrible I still haven't asked Lillian. But I'm beat. Lillian is probably worn out from our intense talk. At least that's what I try to convince myself. Anyway, I decide to postpone that tough, tough question for the following day.

[Hanne:] I had hoped I could spend the rest of the day recuperating by the pool at my hotel. No such luck. Instead, I end up spending my afternoon in a hellish, nightmare of a place called "The Acholi-quarters." Here live refugees from the war-torn northern part of the country. I went with a fellow Dane, a doctor working for a Catholic outreach program. The number of people with AIDS/HIV is shocking, the poverty as deep as the gigantic holes in the road, the hopelessness appeals to heaven as desperately as the primitive south-facing crosses on the many graves scattered among poor shanty houses infested with tuberculosis. There are so many kids here, little potbellied children, who have never learned to say "hello." Fortunately, there are warm, kind-hearted souls always ready to soothe and care for the ill, too. Unfortunately, there are also drunken, unemployed men, who can find nothing better to do than sit around on stools at make-shift bars and drink cheap beer. Some men walk around pulling their bikes, looking very self-important as if they had somewhere to go, something to do. A couple of them shout as we pass.

The truth, of course, is that these men are going nowhere and don't do anything. It is the women who work. And work hard. While the men are drinking their cheap beer, the women are in the quarry, breaking stone with their bare hands from sun-up to sun-down – day after day, year after year until they die from exhaustion or AIDS or both. They are all sick. I talk to some of them and touch their palms, hardened and decorated with large silver-gray yoke-like formations.

"Just feel this," a woman in her thirties says, "feel how rough my skin has become." I nod and touch her hands. They are rough like set cement. Apparently, her soul too has hardened. This woman does not mince words; there is no gentle laughter – so typical of the African people – to smooth over the horrific realities of her life. Her bitterness is not sugar-coated, and she does nothing to conceal the fact that the life she leads is a non-life, centering only on securing the most basic necessities for her and her children. The family is barely getting by, living at subsistence level on the few dollars she makes in the quarry. To me, it seems miraculous that she hasn't given up a long time ago. But this woman, like so many of her colleagues, is an unsung hero who every day makes the most horrendous sacrifices for her children.

— What do you think about during your long, long working day? I ask, after I've let go of her hand.

"Nothing, really. I do worry about how I'm going to feed the kids – I'm losing weight all the time, but other than that I'm in such pain that all I can focus on is getting through the day." Our eyes meet for a split second before she continues her work, crushing stones with slow, lethargic movements. It seems so frustratingly unfair to me. How can we possibly justify the fact that some of our fellow human beings live this kind of life, a life tantamount to slavery. I mean they are just like us, not inferior beings.

That night I get very little sleep. I'm tormented by the thought that I have been far too naïve about the situation here. I'd had dinner with a disillusioned Danish consultant, who spent most of his adult life in Africa.

And while he recognized that Uganda had made great strides towards becoming a more “civilized” country, he had very little hope for the future of Africa per se. He and his wife left Uganda a few years earlier because there was too much lawlessness, too many wayward bullets flying about, and too many gang fights. They moved to Zimbabwe, where, as in Uganda, they, ironically, lived very well on some of the foreign aid funds which he distributes. The situation in Zimbabwe is causing concerns too, he tells me, and his wife longs for Europe. She wants to leave, “before Mugabe’s hot breath ends up scorching her.”

According to the consultant, foreign aid programs have failed completely: “The entire continent is in free fall, plunging into an abyss of corruption. The best we can do is back out. All the billions of dollars we’ve pumped into Africa have only made the situation here worse. We must let the Africans deal with their own problems. I know I sound cynical, but the clan system is based on very antisocial and antidemocratic premises like favoritism and money grabbing. So, unless the clan system is annihilated, foreign aid will merely feed the corruption.”

— What about the women, I manage to ask. They are showing great potential, aren’t they?

The consultant smiles indulgently at me and sips his beer. “The women are OK. I respect them. They work very hard from morning to night, but they will never get any real power here. African men will never allow it. Never!”

[Hanne:] Another critical voice rings in my ear. The voice is that of the Danish doctor from the Catholic outreach program, who took me to the Acholi-quarters. She thinks the AIDS policy is completely misguided. Instead of building AIDS clinics for the moneyed “elite,” all efforts should be focused on reaching poverty stricken people in the cities and remote country villages, where many still believe you can cure AIDS by having sex with a virgin. “What good will fancy and expensive hospitals, offering expensive, superior ARV (AntiRetroViral) treatments, do to stop the spread of AIDS/HIV? Nothing!”

I don’t know what to think, but I get to form my own opinion the next day while going to the doctor with Lillian. Suddenly, I see Lillian in a new role. Here, at the well-appointed British sponsored Mildmay Clinic, the flagship within AIDS research and treatment, she is a humble and vulnerable patient. After her blood pressure has been measured and her weight recorded (both a bit on the high side – you should do exercises, she is admonished) Lillian is checked thoroughly by Dr. Sseruyange, and it is clear that Lillian is a perfect candidate for the best treatment available. But it is also clear that someone has to help her pay for it. Lillian is no upper class lady with good connections. Both Lillian and Dr. Sseruyange know that she won’t be able to afford prolonged ARV treatments. The tricky thing about ARV treatments is that they become more and more expensive as the illness progresses. As the virus mutates the medical components needed become more complex and more expensive. Lillian already pays for the 5 dollar consultation fee and the quarterly blood tests, which cost \$100 because they have to be sent out of the country for analysis.

Ten years ago ARV treatment cost \$900 a month. Now that price is \$150, which, of course, is very encouraging. “We are now able to treat many more people like Lillian,” the doctor explains, while he is writing her prescription. “We are also working on improving the infrastructure, so we can handle more patients. However, we still need to get better labs and get access to the best medication on the market. We still suffer setbacks when the patients can’t afford their treatments. Ideally, we would like all of our patients to be out there as active, walking, and talking members of society,” he says smiling at Lillian, who, at this moment, is busy getting dressed. Today, she has put on her Sunday best, a purple dress, and little gold earrings adorning small, finely shaped ears. Lillian politely attempts to return the doctor’s smile but has to force the corners of her mouth into a smiling position. She is not herself. Here in the hospital, the illness has her in its power; it’s like a hungry vulture with its claws sunk deep into its prey. I find myself shivering in the chilling shadow of death.

In the car, jolting and bouncing across town towards her office at UNASO, neither one of us is at ease. Fortunately, once there, we loosen up. Lillian introduces me to her colleagues and tells me about the work they do at UNASO. They chiefly focus on making sure the concerns of people with AIDS/HIV are heard at meetings where AIDS strategies are decided. An hour later, on UNASO’s terrace, we eat a late lunch, consisting of a kind of yogurt, a couple of rolls, water and Cokes. We eat in silence, the kind of intimate silence you have between good friends. The visit to the hospital has brought us closer together.

Hanne:

— Lillian, would you mind if I asked you some really personal questions?

Lillian:

“Not at all,” she says, “go ahead.”

Hanne:

— How do you feel about death?

Lillian:

“Well, of course, I think it’s sad that we have to die. But I’ve come to terms with my own mortality. To a certain degree, I think, I’m prepared for it because I’ve lost so many people I loved. These losses have pained me greatly, but they’ve also forced me to deal with the inevitability of death.”

Hanne:

— So many people have died in Africa. There have been so many funerals, and you’ve had to say goodbye to so many loved ones. Is it possible that you, as we may tend to think in the West, have become used to death, have become emotionally numb?

Lillian:

“No, definitely not. We mourn our dead as much as we always have. You never get used to death. When it hits, it hits hard. But we’ve had to learn to accept that death is part of life. It’s a process we’ve had to go through.”

Hanne:

— You are HIV-positive, a death sentence in itself. And I was wondering if that makes you always think about it, dying I mean?

Lillian:

“No, I don’t, but only because I’ve taught myself not to. Every time someone close to you dies, it is difficult not to start worrying again. If it can happen to her, it can happen to you, right? But I try to force myself to focus on other things, so I won’t end up spending all my time wondering when it’s my turn. Please don’t get me wrong, though. We mourn the loss of our loved ones – many of our members have died – but we can’t let it get us down. I understand that now. But it isn’t easy. When I went back to work after Alex’s funeral, a priest came up to me and said, “You have come face to face with life.” I was so hurt. Seeing he was a priest, I had expected kindness and understanding, not what I perceived to be a cruel remark. At the time, I didn’t understand what he meant. I do now. You have to face the realities of life if you want to live.”

Hanne:

— This may sound like a cliché, but would you say that your illness in some ways has helped you live a richer life?

Lillian:

“Yes, actually it has. Since I was diagnosed, I have changed my attitude towards other people and my view of life in general. And I’ve somehow gained a new and keener awareness. Today, I’m passionate about life.”

Hanne:

— So, what you are saying is that you go for fun, intense good times?

Lillian:

“Yes, because happiness is the best cure for stress! And I have to avoid stress because it weakens my already compromised immune system. I do everything I can to stay physically fit and that is much easier when you are in a good mood, so I do everything I can to be happy.”

Hanne:

— What makes you happy?

Lillian:

“I’m happy when things go well, when people appreciate my work as they do in the support group, and, definitely, when I manage to get our points of view across at the high-profiled conferences.”

Hanne:

— How about personal relationships?

Lillian:

“Well, that’s a bit tricky...many of my old friends turned their backs on me after I told them I was HIV-positive, so most of the friends I have now have AIDS/HIV. We love and understand each other in ways I’d never experienced before. We have the same issues and hold each other to our promise of living positively with AIDS. I’ve told you what that means: no smoking, no drinking, staying fit and practicing safe sex.”

A bee swirls around my Coke can, I brush it away and try for a casual tone when I ask my next question?

Hanne:

— Is it at all possible to enjoy sex when you are HIV-positive?

Lillian:

“Yes, absolutely!” Lillian bursts into hearty laughter. “Even if you are sick, you are still a human being, and I haven’t experienced any change in that department.”

Hanne:

— You just made a really important point, I think. When AIDS is the topic of conversation, sex is often demonized. It’s as if we forget that it’s also a wonderful way to celebrate life.

Lillian:

“Exactly, happiness and pleasure are part of sex. And that is what living positively with AIDS is all about. So having and enjoying sex is one way of ensuring a long life. And it is a shame many are advised to avoid sex when they test positive. As long as you practice safe sex, it is OK.”

Hanne:

— To give that kind of advice sounds almost as if they were trying to punish the person?

Lillian:

“Yeah, it ends up being perceived as punishment, and we always tell people to go ahead and have sex, if that is what they want. Of course some lose interest in sex because it was sex that got them sick in the first place. I recently met an HIV-positive woman in a village who hadn’t had sex for four years. She was so disgusted with the whole thing. She didn’t want to learn about how you get infected or how she could avoid infecting others. A woman like that, we obviously don’t talk to about safe sex. But then there are those who can’t live without sex, and these people we educate.”

Hanne:

— You are no puritan, are you?

Lillian:

"No, I like having sex and going out. I drink alcohol but in moderation. I love hanging out with my friends, listening to music and dancing. But I also love spending time with my daughter. We've been apart many times since she was an infant. When Alex was sick, other people had to care for her. And later, I had to leave her when I went to the various workshops. So we've been forced by circumstance to accept separation as part of our life. Now, however, I have a feeling that she needs me more, and I need her too. I want to give the very best a parent can give a child: The best elementary schooling, high school and a college degree. I also want her to have a rich social life. And I think it is important that I start telling her about my life. She should know where I come from... the tragedies, the awfulness...."

The image of Barungi, fluttering about like a butterfly, pops up in my mind like a black-edged snapshot. I swallow hard.

Hanne:

— OK, tell me about your background?

Lillian:

"I come from a small village in the country. There were six girls and one boy and, as I told you, I was the oldest. Three of my siblings are dead now. We were so poor that my parents couldn't afford to keep us in school after the third grade. So I started paying for my own tuition from my tenth or eleventh year. I hauled water and worked in the fields. Luckily, I did really well in school and won a scholarship, which paid for the rest of my schooling. Also there was a nun and a priest who always gave me pocket money. Of course they meant for me to spend it on luxury items such as chewing gum and pens, but I used the money to pay for tuition for my younger siblings – two sisters and my brother. And I'm glad I did that. Today, one has graduated from college, another is finishing a degree and the third enrolls at university next year."

Hanne:

— How many girls from your village got an education?

Lillian:

"Neither girls nor boys went to school. There were only a few my age who even wanted to go to school."

Hanne:

— Why did you want to go to school?

Lillian:

"Well, we were miserable at home. We were so poor. We barely had enough to eat let alone decent bed linen or clothes. My mom worked incredibly hard every day, but we didn't have enough land for her labor to pay off. And I realized that the only way out for me was an education."

Hanne:

— As a little kid, when you were hauling water for other people, what were your hopes and dreams?

Lillian:

"Oh, I daydreamed, of course," Lillian laughs apologetically. "I wanted to be somebody. Someone important. You see my childhood home was very violent. My dad beat up my mom on a regular basis and threw her out of the house, and of course, we kids went with her. I never wanted that for my kids. In my daydreams, I had a nice family full of love."

Hanne:

— "Did your dad ever beat you?"

Lillian:

"Yes, when my dad was after my mom, he beat us too. Naturally we tried to protect her, so often the

punches meant for her landed on us because we were in the way. Sometimes we stayed away from the house for days, and we'd have to sleep out in the open. My dad was an alcoholic, and it was when he drank he got violent and beat us."

Hanne:

— It was quite common in the village for the men to beat up their wives though, wasn't it?

Lillian:

"Yes, it was, but my dad was worse than the other men. Our situation was really horrific."

Hanne:

— So you daydreamed about getting out of there?

Lillian:

"Yes, and I have, even if I haven't become an important person yet. I was disappointed in myself in college because I didn't make good grades, so I settled for a teaching degree. I had really wanted a college degree. But if all goes well, I'll get one. I recently enrolled in a social studies program. I work during the day and go to school at night. I'm not making enough as it is, and only a college degree is going to get me a bigger paycheck. And I need the money for medication if I'm going to stay alive. So I have to, don't I?"

I nod emphatically. Yes, she must! Her and all the others!

Hanne:

— When you look back on your life, do you feel that the oppression of women and girls is a serious issue?

Lillian:

"Yes, absolutely. Boys are still considered more worthy than girls. In my village, boys are still much more likely to get an education than girls."

Hanne:

— Statistically, many more women than men have AIDS/HIV, and this is true for the younger generation as well. Why do you think that is?

Lillian:

"Because women are powerless in our culture. They can't own property, all inheritance goes to the men, and they have no means of defending themselves in a system like this. Women live at the mercy of the men in their lives. Offending a man could basically cost a woman her life. And this is why they don't say no when a man demands sex."

Hanne:

— Does women's powerlessness explain the disproportionately higher rate of AIDS/HIV?

Lillian:

"Yes, but men's irresponsible behavior is also at fault. Married men refuse to accept their own illness or the risk of infection. They go out on the town and have affairs with young girls, infecting them or getting infected themselves. Afterwards they bring it home to their wives."

Hanne:

— I've heard that more and more Ugandan wives are choosing to sleep in separate beds because they don't want to sleep with their philandering husbands.

Lillian:

“That’s funny! It’s probably true too.” Lillian laughs.

Hanne:

Her laughter is encouraging, and I ask her if she thinks that the AIDS epidemic will help unite women and open their eyes to all the injustices. Will the epidemic, in other words, even in the midst of all the tragedy, bring about a positive change?

Lillian:

“Yeah, I actually think that could happen. The epidemic has already made us realize that things must change and has pointed us in the right direction. Women have been forced to fight for themselves and their children. The “fighting” has helped us become more assertive. At the various women’s organizations, the women are marching forward with great speed. Among AIDS activists, it is the women rather than the men who do the traveling now. We approach things differently. Men die in great numbers too, but they seem to prefer to live in denial rather than become proactive like the women.”

Hanne:

— Don’t you think women are able to deal better with AIDS/HIV because they are in general more open about things than men?

Lillian:

“Maybe. Statistically, women survive much longer than men. I see it in my own support group: the men don’t want to get out of the closet.”

Hanne:

— So are you saying that in twenty years when we look back on the AIDS/ HIV epidemic, we’ll be able to say that it was the epidemic that brought African women out of their bondage and into freedom?

Lillian:

“Well, it has certainly been my own experience. Before I got sick, I didn’t approach life the way I do today. And this is true for all the women in the support group. They have all become fighters. They fight for themselves, their kids and for those who don’t have the energy to fight.”

Hanne:

— Do you think that African society will change radically if the women are empowered?

Lillian:

“No doubt about it! If we women make good, it’ll change the political, economical and social structure of our society completely. If women were in power, they’d create a true democracy. They’d focus more on education, healthcare and social conditions. And they’d definitely be less corrupt. I’m not implying that women can’t be corrupt – they can be appalling! But in general women are less corrupt than men.”

Hanne:

— If we met then years from today, what would you be doing?

Lillian:

“Well, if I weren’t a member of parliament, I’d probably be…” Lillian grins.

Hanne:

— You’d be in politics, really?

Lillian:

“Yes, I would. I’m very interested in politics and sooner or later I think I’ll run for Parliament.”

Hanne:

— Why?

Lillian:

“I want to be part of the decision-making process. Too often policy makers have no idea of what’s going on in the real world. The AIDS/HIV epidemic is a good example. People are dying like flies, yet the politicians claim the situation is under control. It makes you wonder if they even know how sick we are. I think a person like me could make a difference. For now, though, I’ll concentrate on my little community. If I manage to make a difference here, I don’t see why I couldn’t do it in a larger setting as well. I might just be ready to run for the 2006 election. I’ll run on my own agenda, though, not for The Movement.”

Her last remark is made with great conviction. She has clearly thought long and hard about this.

Hanne:

— OK, so you’re an MEP in ten years, what else?

Lillian:

“Gosh? What else?” Lillian considers the question with the expression of a housewife planning a party. In 2004, I’ll definitely have a car, and maybe I’ll have a baby. I haven’t decided on this last bit yet. Maybe it is not a good idea when I’m on ARV. I’m not completely sure about my relationship with my boyfriend either. Maybe it’s too shaky. So... the car comes first. A car would make my life so much easier, driving to the clinic and to visit sick members of our group. Sometimes, when I feel sick myself, it is hard getting in and out of busses to go places. So definitely, a car would make my life easier and much more fun.”

Hanne:

— Do you plan to remarry?

Lillian:

“I must admit, I don’t really know. First of all, I’m not sure we are that serious about each other Robert and me. And if I marry again, it’ll be for life. I don’t want to have to face a divorce in two or three years. Secondly...yes, secondly, I’m no longer willing to let a man have power over me. And African men expect their wives put up with everything. I don’t ever want to do that. I want to live my life as I please – not according to some man’s needs and desires. I want to be free.”

Hanne:

— Then you’ll never marry?

Lillian:

Lillian laughs. “No, probably not. If I married Robert, I’d have to move out of my house because no man would live in his wife’s home. And I have no intention of giving up my house, so you are right, I probably never will marry again.”

Hanne:

— How long do you think you will live, Lillian?

Lillian:

“A very long time! I don’t think about dying. I have too much to do, and I firmly believe I’ll make it.”

Hanne:

Lillian is back to her natural state of rambunctious joy, and death has been shooed away. In the hospital it was very real; now it is merely a theoretical possibility. And I feel like the devil's advocate when I ask my final question:

— Have you had Barungi tested?

Worry lines appear on the high forehead, and Lillian shakes her head slowly from side to side.

Lillian:

"No, I haven't. I don't think she is HIV-positive. She is six years old now, and has shown no sign of illness. But I know I ought to get her tested. I just haven't had the courage. Do you understand?"

Hanne:

I understand. Anybody would.

As I'm getting into the car, after we've said our final goodbyes, Lillian motions me to come to her side. She is very tense, and I know what she is about to say is very hard for her.

"I hate to beg," she says. "But if you think of someone who might be able to help me pay for my medication, I would be very grateful."