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Growing Up HIV Positive



Young people who grow up HIV+ face more psycho-social challenges than their peers as they enter into adolescence and adulthood. Credit: Natasha Taye/IPS

By Dorine Ekwe

YAOUNDÉ - "I didn't get to choose. How is it that out of my mother's fourteen children, it was me, the last born, who was infected?" laments Arlette*, an 18 year old girl from Cameroon who was born HIV positive.

Speaking at the offices of Positive Generation, an anti-AIDS organisation for people infected and affected by HIV/AIDS and tuberculosis, Arlette immediately loses her open smile when the subject of her HIV status comes up.

Her memories from the day she was born to now are of endless illnesses and swallowing pills every day. She tells Terraviva: "I have to take two large tablets without food in the morning and another dose in the evening. Sometimes I want to end it all." Feeling her despair, her mother tries to comfort her.

Arlette's mother Christine Banga* is a retired nurse aged 66. They only found out about her daughter's HIV status when she was 10 years old. "In the 90s the issue of HIV was taboo in Cameroon. I brought my child into this world not knowing that I was infected," she reveals.

"She fell sick very often. Eventually, we both tested positive. I feel guilty and I don't want to lose her," Banga says, adding that she had another child who was born HIV positive who died.

Even though the whole family knows about her HIV status, they have hidden it from the rest of the community. "They would point and laugh and call out 'that one, she has AIDS.'" This reality makes her bitter and angry with her mother whom she accuses of not giving her a chance to live like other young people: healthy and without constraints.

Her psycho-social counsellor, called Aunt Sylvie, always tries to calm her outbursts. She stresses that Arlette's aggression is not unusual and that it is important to bring together children born with HIV so that they make sense of what is happening to them. "It makes things less stressful for them."

The meetings organised by the counsellor for people born with HIV help young Arlette to accept her status rather than go into denial which tends to happen.

A year ago, after several hours of prayer, a pastor told her that she was cured of her illness. "I refused to take my medication. I told myself, 'I am never sick, I am beautiful, I can't have the HIV virus,'" she recounts, disillusioned.

Stopping the treatment almost proved fatal. Now she has moved from first line to second line treatment. This is a harsh blow for her family who are afraid that she will be placed on the third generation drugs that are not yet available in this Central African country.

Despite the introduction of the Prevention of Mother-to-Child Transmission programme (PMCT) in 2000, babies continue to be born HIV positive in Cameroon – 5 800 in 2012, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS).

The HIV prevalence rate in pregnant women varies from 5 to 12 per cent across the various regions of Cameroon. But four out of ten pregnant HIV positive women do not receive PMCT.

According to UNAIDS, nearly 5000 children are receiving antiretroviral treatment compared to the 35000 need it.

*Not their real names to protect their identity.

La stigmatisation, l'autre virus nocif

Par Ulrich Vital Ahotondji

COTONOU - Tôt le matin, beaucoup de malades du SIDA se bousculent pour recevoir des antirétroviraux (ARV) à l'hôpital de zone de Suruléré, à Cotonou, au Bénin - l'un des 89 sites de prise en charge des personnes vivant avec le VIH (PVIH) dans ce pays d'Afrique de l'ouest.

Fatou Agamba*, 30 ans, le regard scrutant l'horizon, n'a pas la force de se battre comme les autres, visiblement affaiblie par sa grossesse de six mois. Elle s'assoit par terre, une main sur la tempe. «J'ai le SIDA depuis 2008 et je suis ici pour prendre les ARV», dit-elle à TerraViva. «J'ai beaucoup de malaise avec ces médicaments que je dois prendre toute ma vie en me cachant. C'est vraiment pénible!»

Selon Dr Moussa Bachabi, chef-service du suivi-évaluation au Programme national de lutte contre le SIDA (PNLS), le Bénin comptait, en juin 2013, 22.937 malades sous ARV, dont 1.268 enfants et 609 femmes recensées pour la Prévention de la transmission mère-enfant (PTME).

Phina Amégan* fait partie des 609 femmes sous ARV au Bénin. Elle est aussi engagée dans la lutte contre le SIDA en tant que médiatrice.

Lorsqu'elle a connu son état sérologique en 2000, elle s'est dirigée vers la mer pour se suicider avant d'être sauvée, raconte-t-elle à TerraViva.

«L'idée de vivre tout le reste de ma vie avec cette maladie, à prendre des comprimés, m'a tout de suite répugnée; et le comble, ce sont mes parents» qui ne supporteraient pas

la nouvelle, affirme-t-elle. «Survivre avec le SIDA au Bénin est un véritable challenge. Il est très difficile de respecter les heures des prises quotidiennes, de supporter les effets secondaires et de se cacher».

Selon Lucien Hountohou, président de l'association Action, espoir et vie, «plusieurs malades abandonnent le traitement pour des raisons de pauvreté extrême et de stigmatisation. Pour éviter de se faire indexer dans la rue, ils quittent le nord du Bénin pour le sud pour se faire soigner».

L'accompagnement psychologique des séropositifs est délicat, déclare Wilfried Djogbénou, psychoclinicien au Centre de traitement ambulatoire des PVIH à Cotonou, la capitale économique béninoise. «Nous les amenons à accepter leur état, à se déculpabiliser, à suivre le traitement, et à espérer que la vie est encore possible avec cette maladie».

Dr Aldric Afangnihoun, gestionnaire d'un site de dépistage et de prise en charge des PVIH à Cotonou, souligne que «les malades réagissent bien et vivent bien lorsqu'ils sont pris en charge sans discrimination et avec un suivi personnel. Mais la stigmatisation dans notre société reste un mal pernicieux».

Camélien Bernard Moegle, un prêtre infirmier sur le site de Davougou à Abomey (centre-sud du Bénin), estime que le principal problème vient des 'perdus de vue': des malades qui «disparaissent et abandonnent le traitement à cause de la stigmatisation, la pauvreté». Soutenu par l'ONG Plan Bénin, ce site offre une prise en charge in-

tégrale aux malades.

Selon Dr Amédée de Souza, chef-service de la prise en charge médicale des personnes séropositives au PNLS, le Bénin compte aujourd'hui quelque 63.000 malades du SIDA dont 31.000 ont besoin d'ARV, mais seulement 26.000 environ en bénéficient actuellement (en novembre), soit 83,87 pour cent.

Les ONG du Réseau béninois des associations de PVIH affirment que les ruptures cycliques des ARV n'aident pas à améliorer l'état de santé des malades et pourraient développer la résistance aux médicaments chez les malades et entraîner le besoin des ARVs dites de deuxième ligne, plus chères.

Dr Mireille Ahojo da Silva, chef-service des stocks au PNLS, reconnaît l'existence des ruptures d'ARV et de réactifs, mais qui ne dépendent pas d'eux. «Nous faisons nos quantifications et exprimons nos besoins en temps réel, mais les procédures du Fonds mondial et du budget national sont très lourdes. Jusqu'à l'heure où je vous parle, nous n'avons reçu aucun stock de 2013 ni du Fonds mondial ni du budget national», déclare-t-elle.

Les ONG appellent les dirigeants du pays à mieux régler les problèmes de prise en charge pour lui éviter «de se retrouver avec beaucoup de malades en deuxième ligne alors que le Bénin n'est pas préparé à cette situation».

* Ce sont des noms d'emprunt pour protéger leur identité.



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OPINION

Young People Today. Time To Act Now

By Prof. Sheila Tlou

JOHANNESBURG - On 6-7 December 2013, education and health ministers from 21 countries in Eastern and Southern Africa will gather in Cape Town, South Africa, to agree on a political commitment based on UN and civil society supported recommendations on the need for sexuality education and sexual and reproductive health services in the region. These recommendations have the potential to bring about critical improvements in the education, wellbeing and life chances of millions of young people as well as the development of the region as a whole.

Yet, during this meeting, the futures and lives of millions of young people will hang in the balance as ministers decide whether or not to take the recommendations on board and commit to bold actions which are needed now. This is why I am raising awareness of the issues at stake, the decisions ministers will take and the impact of their decisions on the millions of young lives today, and millions more in the future.

The ministerial meeting on 6-7 December will be a defining moment for the HIV epidemic, for young women and a turning point in the history of how we empower adolescents and young people to exercise their rights to education, health and citizenship. As young people, parents, teachers, leaders and decision-makers – together – we must do everything we can to ensure our education and health ministers are aware of these issues and the solutions proposed and make sure they commit to take urgent action for adolescents and young people today.

With all the evidence pointing to the benefits that comprehensive sexuality education (CSE) and sexual and reproductive health (SRH) services can provide in a rapidly changing society, why is it so vital that the region's health and education ministers make this commitment in December?

A new report on the region - *Young People Today. Time To Act Now* - provides many of the answers. In terms of HIV there has been very encouraging news recently – 6,3 million people are on treatment and far larger numbers of people are living longer and healthier lives. Also, the rates of new infections are declining in some countries in the region. Despite this, we are still seeing 430,000 new HIV infections per year occur among people



Prof. Sheila Tlou.

aged 15-24. That translates to 50 new infections every hour, with the majority occurring among young women. It is notable that thirty years into this epidemic, less than 60 percent of young people in the region still don't know basic facts on preventing HIV infection.

Central to the recommendations is the need to provide – at scale – a combination of CSE from primary school onwards and SRH services, thereby creating an integrated approach with adolescents and young people at the centre. These actions will see ministries working together to increase the support to adolescents and young people so they can lead healthier, more informed and responsible lives. The report's recommendations are do-able and cost-effective – and will save young lives.

We cannot afford to be complacent and let this situation continue. Currently, 2.6m young people are living with HIV – education and health have the mandate, the resources and the responsibility to make an AIDS free future a reality for the next generation. Yet this will only happen if we enable teachers and health providers to reach out to young people with appropriate education, information and access to services and commodities.

As well as HIV, many other sexual and reproductive health issues are challenging young people. These include high levels of early and unintended pregnancies and high levels of maternal deaths. As the global community looks back on how far we have come since the International Conference on Population Development (ICPD) in Cairo 20 years

ago, and as we gear up for a post 2015 agenda, we need to change the narrative in our region. The ICASA meeting of education and health leaders offers a huge opportunity. We need to ask ourselves if we have delivered on what was promised by way of providing young people with the best start in adult life and giving them everything they need to make informed decisions to negotiate the realities of the 21st century.

Ministries, civil society organisations - including youth organisations - and a wide range of stakeholders in education and health are already involved in meetings at country level on what needs to go into this ministerial commitment. The partners in this initiative are ready to support us in implementing the changes. I am totally committed to making sure our adolescents and young people have what it takes to lead healthier and more informed lives, where they make decisions about their own futures. If you are a parent, a teacher, a community leader and most of all a young person anywhere in the region, find a way to make your voice heard. With less than a month until the 6-7 December ministerial meeting and the ICASA conference in Cape Town, I urge you to talk with your ministers of health or education and talk to UNAIDS, UNESCO, UNFPA and UNICEF country offices. We must make sure that young people's futures are recognized, valued and protected. It's time to act now.

Prof Sheila Tlou is Regional Director UNAIDS and Chairperson, High Level Group on the ESA Commitment

For more information see www.youngpeople-today.net

A Shortage of ARVs and a Surplus of Stigma in Côte d'Ivoire

By Fulgence Zambélé

A BIDJAN - At the Cocody-Anono community health centre, south-east of the Ivorian economic capital of Abidjan, Bertine Bahi* regularly attends awareness sessions on Preventing Mother-to-Child Transmission (PMTCT) for women living with HIV.

Bahi tested positive in her third month of pregnancy. In October, the 32-year-old was five months pregnant and still had not revealed her HIV status to her husband.

“Despite the midwife’s advice, it is difficult to tell my husband. If I do, I will be thrown out of my home,” Bahi says. “For now, when I can get hold of antiretrovirals (ARVs), I take them in secret.”

Suzanne Asseman*, a 37-year-old housewife from Agboville in southern Côte d'Ivoire, learned she was HIV-positive in June 2012. She has to travel to Abidjan, 80 kms away, for the ARVs that keep her healthy.

This is not easy because Asseman is seven months pregnant. When she finally received her ARV pills for October, she had missed five weeks of treatment. ARVs must be taken regularly every day or their efficiency is compromised.

Asseman has always waited one or two weeks to get her medication, but this time the wait was longer. Now she has doubts about her treatment.

“I was reluctant to go on ARVs. Where I live, the medication has expired by the time it gets there,” she confides to IPS. “I think I would rather stop taking the drugs than keep up all the running around.”

Rolande Yao, a social worker in the PMTCT centre in Attécoubé in central Abidjan, says that stigmatisation is increasing, and the frequent disruptions in ARV supply create yet more difficulties for patients.

Three out of 10 pregnant women living with HIV in Côte d'Ivoire miss out on PMTCT, says the Joint United Nations Programme on HIV/AIDS (UNAIDS) in its 2013 Progress Report on the Global Plan.

Testing pregnant women for HIV often puts a strain on couples’ relationships.

“When a man is told his wife is HIV-posi-



A health worker explains the sexual transmission of infections at the family planning clinic in Yopougon. ARV shortages and long waits discourage women from starting or staying on treatment. Credit: Kristin Palitza/IPS

tive, often he suspects her of being unfaithful,” says Yao. “He may refuse to be tested and reject his wife.”

Yao estimates that seven out of 10 women experience rejection and that, despite intervention by medical staff, many husbands refuse to take them back.

Fear of rejection prompts pregnant women who have tested positive to change their health centre or to keep silent. Others become lost to the medical system, avoiding antenatal medical care and risking passing the virus to their babies, Yao adds.

According to Cyriaque Ako, coordinator of the M2C (Mother to Child) project, many of these lost cases make their way to traditional healers.

M2C works in Yopougon, the country’s most populous community, near Abidjan, where women prefer to go to healers and many do not know about PMTCT, explains Ako. The project, now in its second year, aims to link women from 15,000 poor households to health and HIV testing centres.

The HIV prevalence rate is 3.2 percent in this West African country with a population of 20 million, which struggles to contain the epidemic and care for its estimated 450,000 HIV positive people, according to UNAIDS.

Some modest progress is visible. UNAIDS points out a decline in the number of children newly infected every year, down from 6,700 in 2009 to 5,000 in 2012. “Declining, but not rapidly enough,” says the Progress Report.

However, AIDS non-governmental organisations (NGOs) complain that since the end of the

2011 to 2012 post-electoral crises, people living with HIV seem to have been abandoned. The NGOs have regularly sounded the alarm on the repeated ARV supply disruptions.

One of the main causes of the ARV shortage has been the collapse of the health system over a decade-long political crisis, starting with an armed rebellion in the north and west of the country and simmering into post-electoral conflict.

During this period, the international community imposed arms and trade embargoes on Ivorian ports – Abidjan and San Pedro – in order to force former president Laurent Gbagbo to leave power after his electoral defeat. Medicines ordered from Europe could no longer be delivered to Côte d'Ivoire. In addition, many health facilities were looted and closed temporarily during the fighting, according to the NGOs.

Yaya Coulibaly, president of the Ivorian Network of People Living with HIV, which is known by its French acronym RIP+, says “community advisors and prescribing doctors have to lie to patients because there are not enough ARVs at the government pharmacy.” Even the basic ARV Nevirapine, which is prescribed for PMTCT, is in short supply, he says.

Coulibaly explains that at times ARVs are available in abundance in certain health centres but in short supply in others, pointing to a distribution problem. At the Ministry of Health, he adds, a revamp of the government pharmacy is underway to improve ARV distribution. This will help mothers like Asseman and Bahi stay on treatment and healthy.

*Not their real names

VOICES FROM THE STREETS

Tshepo, Ayanda and HI Vee

By Zandi Mqwathi

Some things just go beautifully together

Like...

Peanut butter and jam sandwiches,
Chocolate chip cookies and milk,
Fish and chips,

Boys and girls. Or at least that's what adolescent boys think and what adolescent girls talk about too: Love.

This love, unfortunately, comes disguised as unprotected sex, transactional sex and inter-generational sex.

As I write this, I am reminded of my very first "crush" in high school, how excited I used to get just to see him and have him pass me by like blowing wind. Perhaps you too can relate to this crazy, wild and beautiful teenage phase - most of us, if not all, have once wished to be noticed by that boy or girl at school regardless of our race, class and status.

Truth is...there is another aspect of the teenager's life that most of us are not even aware of, maybe because we have never experienced it or we aren't paying enough attention. Statistics show that:

- More than two million adolescents aged 10 to 19 years are living with HIV, marking

a 33 percent rise since 2001. (World Health Organization, 2013)

- Southern Africa is home to 1.2 million HIV-infected adolescents whose long-term health depends on their strict adherence to antiretroviral therapy. (UNICEF, 2013)

In communities where dating or relationships are not frankly discussed amidst young people, my experience has taught me there is a high chance that young people will engage in sexual activities to discover the fuss behind "If you fall pregnant, I am going to chase you out" that our mothers used to yell at us to scare us from even allowing boys to touch or kiss us.

Those words failed dismally. In fact, they served as a catalyst to our "first times". And, as they say, curiosity killed a cat.

So what happens to HIV positive adolescents when they start developing sexual feelings or having sex? To gain more insight, I had a chat with Tshepo, a 22-year-old young man who was born with HIV.

Our conversation was centered on relationships and HIV. Although Tshepo is new to the dating scene, for him the most important aspect of a relationship is trust

I think we can all learn a lot from that. I mean, taking time to know someone way before the

first kiss and then oh my! make it or break it moment.

Disclosing is essential, he said with confidence. In my mind, I asked myself, well, Tshepo, what about rejection? It was as if he could read my mind! He said: "One must never risk infecting a partner regardless of what the outcome might be afterwards".

How many of us do that? This is a tough step that needs to be taken way before we go between the sheets. Since it is already difficult for most people to get tested, let's switch on the light bulb of information and start making informed decisions. Go out... Wait...Give it time...And give it time.

Zandi "Princess Zar" Mqwathi is a confident, innovative young leader and former radio personality with a drive to use her craft and experiences to educate and empower other young women.



References

www.timeslive.co.za
www.bdlive.co.za



What are the pressing issues surrounding HIV/AIDS and youth?

By Nqabomzi Bikitsha



Education. The youth needs to be educated from an early age about sex and condoms. They need to start thinking about their future and making better choices.

Puleng Kwena, South Africa



The priority needs to be the prevention of new infections, and encouraging the youth to get tested.

Albert Oppong-Ansah, Ghana



Lack of information is a serious issue. People need to understand that this is a serious issue and that every time they have sex without a condom there are risks.

Samuel Mugadi, South Africa

Une vie avec le VIH



Por Dorine Ekwè

YAOUNDÉ - «Ils ne m'ont pas laissé le choix. Sinon, pourquoi sur les 14 enfants qu'a eus ma mère, c'est moi, la dernière, qui suis malade?», se plaint Arlette*, une jeune fille de 18 ans née séropositive au Cameroun.

Rencontrée à au siège de 'Positive Generation', une association anti-SIDA constituée de personnes infectées et affectées par le VIH/SIDA et la tuberculose, Arlette perd immédiatement son sourire candide lorsqu'on évoque son statut sérologique.

De ses 18 ans de vie, elle dit ne se souvenir que de ces maladies incessantes pendant son enfance et la prise quotidienne de médicaments. Elle raconte à TerraViva: «Je dois prendre deux gros comprimés à jeun le matin et deux autres le soir. Souvent, je veux en finir». La sentant troublée, sa mère tente de la reconforter.

Fille d'une infirmière retraitée de 66 ans, le statut sérologique d'Arlette est connu à l'âge de 10 ans. «Dans les années 1990 au Cameroun, le VIH était tabou. J'ai mis ma fille au monde sans que je sache que moi-même j'étais infectée», confie Christine Banga*, sa mère.

«Elle était souvent malade. Finalement, elle a été dépistée positive et moi aussi. Je me

sens coupable je ne veux pas la perdre», indique Banga à TerraViva, ajoutant qu'elle avait eu un autre enfant né séropositif qui est décédé.

Si toute sa famille est informée de son statut sérologique, Arlette et les siens le cachent à leur entourage. «On se moquerait de moi, me montrerait du doigt en disant: celle-là, elle a le SIDA». Une éventualité qui la rend amère face à la vie et agressive contre sa mère qu'elle accuse ne lui avoir pas donné la chance de vivre comme tous les jeunes: sains et sans contrainte.

Sa conseillère psychosociale appelée Tantine Sylvie tente toujours d'atténuer ses crises de colère. Elle affirme que cette agressivité n'est pas propre à Arlette et qu'il est important de mettre ensemble les enfants nés séropositifs pour qu'ils comprennent ce qui leur arrive. «Cela devient moins stressant pour eux».

Toutefois, des rencontres organisées par cette conseillère psychosociale avec d'autres personnes nées avec le VIH, permettent de rassurer et de faire accepter son statut à cette fille qui a tendance à sombrer dans le déni.

Il y a un an, un pasteur lui a affirmé, après quelques heures de prière, qu'elle était

guérie de sa maladie. «J'ai refusé de prendre mes médicaments. Je me suis dit: je ne suis jamais malade, je suis une belle fille, je ne peux pas porter le virus du VIH», raconte-t-elle, désabusée.

Cet arrêt du traitement lui sera fatal: elle passe des médicaments de première ligne à ceux de deuxième ligne. Un coup dur pour sa famille qui craint qu'elle ne soit placée en troisième génération, qui n'existe pas dans ce pays d'Afrique centrale.

Malgré la mise en place d'un programme de Prévention de la transmission mère-enfant (PTME) en 2000, des bébés continuent de naître séropositifs au Cameroun – 5.800 en 2012, selon le Programme Commun des Nations Unies sur le VIH/SIDA (ONUSIDA).

La prévalence de l'infection par le VIH chez la femme enceinte varie de cinq à 12 pour cent selon les régions du Cameroun. Mais quatre femmes séropositives enceintes sur dix ne sont pas protégées par la PTME.

Presque 5.000 enfants sont en traitement antirétroviral, mais 35.000 en ont besoin, selon l'ONUSIDA.

* Ce sont des noms d'emprunt pour protéger leur identité.