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A Testimony of Human Resilience: Close-up with Mr. Brandford Yeboah on living with HIV in Ghana for 24 years

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PDA INTERVIEWS AND EXPERT OPINIONS

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INTRODUCTION

As part of the celebration of World AIDS Day in December 2015, PDA staff interviewed Mr. Brandford Yeboah, a living testimony of how a person living with HIV (PLHIV) can face and overcome the threats of the disease. He has lived with HIV for 24 years, even though he has only been on anti-retroviral drugs for three years. Mr. Yeboah is the national vice president and a pioneer member of the Ghana Network of Persons Living with HIV (NAP+), which was established in 2005. NAP+ comprises 350 member support groups spread across Ghana, with over 240,000 registered members.¹ NAP+ is governed by a National Executive Committee (NEC) made up of the president, vice president, treasurer and secretary. It also has regional executive committees in every region. The main role of NAP+ is to provide support for efficient management of the disease. Mr. Yeboah has been instrumental in mobilizing PLHIVs at both the regional and national levels.

Overview of Ghana's current HIV/AIDS profile

As a backdrop to the interview, it is important to have an overview of Ghana's HIV profile. There are over 224,000 persons living with HIV (PLHIV) in Ghana;² with the 2014 adult prevalence rate estimated to be about 1.4 percent.³ Some 28,000 children and 120,000 women were estimated to be living with

¹ According to the NACP Sentinel Survey 2013

² Ghana AIDS Commission (2014), 'Summary of the 2013 HIV Sentinel Survey Report', http://ghanaiids.gov.gh/gac1/aids_info.php ; UNICEF (2013), 'At a glance: Ghana', http://www.unicef.org/infobycountry/ghana_statistics.html (Last accessed November 22, 2015)

³ PEPFAR (2015), 'Partnering to achieve epidemic control in Ghana', <http://www.pepfar.gov/documents/organization/199362.pdf> (last accessed November 1, 2015);

HIV/AIDS in 2012; with 190,000 children orphaned by the disease in 2012.⁴ With funds for HIV/AIDS programmes dwindling and very little sign of attaining 'zero new HIV infections, zero discrimination and zero AIDS-related deaths', there is a need to redouble Ghana's efforts at addressing the AIDS pandemic.

Some of the factors identified as obstacles to attaining the zero mark by the Ghana AIDS Commission (GAC) have been classified into preventive and management factors.⁵ According to the GAC, the factors that obstruct preventive measures include the following: one, the slow implementation of behavior change communication (BBC) or information education communication (IEC) strategy; and two, the inefficiency in targeting and preventing infections among vulnerable populations such as the youth and most at risk populations (MARPs). The MARPs include men who have sex with men (MSMs), female sex workers (FSWs) and their clients, and migrant populations. The third challenge is the low condom use, even for higher risk sexual intercourse, which according to the 2008 Ghana Demographic and Health Survey, was 46 percent for young men and 28 percent for young women. The fourth is the persistently low coverage of prevention of mother-to-child transmission (PMTCT) of the disease. The GAC further states the following as challenges militating against safe management of the disease for a dignifying life: i) low coverage of HIV testing, counselling and treatment; and ii) the low use of post exposure prophylaxis (PEP) and universal precautions. Others include the huge unmet needs for anti-retroviral treatment (ART) services; inefficient monitoring and quality of care for PLHIVs; low coverage rates for treatment for opportunistic diseases; and weak integration of nutrition within HIV related health services.⁶ The situation looks challenging, but from Brandford's experience, there is every reason to believe that with the right attitude to life and appropriate institutional support, HIV does not have to be a life-threatening disease for PLHIVs in future.

For four years, from 2011 to 2015, the global theme for the celebration of World AIDS day led by UNAIDS has been targeting and achieving zero new infections, zero discrimination, and zero AIDS-related deaths. The following conversation with Brandford Yeboah was initiated by PDA in order to better understand the realities of the most affected populations and thus the need for major stakeholders and all of us to join together to attain the goals of the theme for celebration as a matter of urgency. The conversation thus aims to shed light on the realities and possibilities of living with the disease in Ghana.

THE INTERVIEW

PDA: Can you tell us a little bit about yourself?

BY: I am 50 years old, married, and have lived with HIV for 24 years. February 2016 will be the 24th anniversary of my diagnosis. After our first child died of HIV soon after birth, we were counselled for a test; and we tested positive. It was the most difficult moment in our lives. At that time, the stigma

UNAIDS (2014), 'Ghana: HIV and AIDS estimates',
<http://www.unaids.org/en/regionscountries/countries/ghana/> (last accessed November 22, 2015)

⁴ UNICEF (2013), Op. Cit.

⁵ Ghana Aids Commission (2010), *National HIV & AIDS Strategic Plan 2011 – 2015: Towards achieving universal access to comprehensive HIV services* (Accra: GAC)

⁶ Ibid. pp. 20ff

against PLHIVs was at its peak, HIV was relatively new in Ghana, and was perceived to be a deadly disease. The trauma was unimaginable. Today, I have two children who are both HIV-negative.

PDA: So how did you overcome this initial trauma?

BY: It was not easy at the time, but as a Christian I see blessing in every misfortune. A team of PLHIV were invited by UNAIDS to give testimony in Ghana, some of whom had lived with the disease for 12 and 17 years. This gave impetus to my wife and I to want to live again. I am planning on publishing a book to commemorate my 25th anniversary as a PLHIV, to be entitled: 'Living with HIV for 25 years'. Look out for that book!

PDA: You have lived quite long and well with the disease. What is your secret?

BY: Positive living! Accepting the result as it is! Firstly, I did extensive reading to become enlightened about the disease, the dos and don'ts. Secondly, I exercise frequently. I do things like leisure walking, jogging, and running. I prefer to walk short distances than to take a taxi or transport. Thirdly, I pray and trust in God. I am a Sunday School teacher, a lay preacher and Christian activist. These give me a lot of inspiration.

PDA: As a person living with HIV, how do you deal with stigma?

BY: I now have rich experience. I have lived with the disease for 24 years, during which time I have had 2 children who are HIV negative. I do not hesitate at all to engage people who show stigmatizing behaviour. My message for these people is simple: "When you point one finger at someone, four fingers point back at you. I know my status, you do not know your status? Maybe the disease that you are carrying is more dangerous than what I have." There are other dangerous diseases such as Hepatitis B, which is even more dangerous. Now we see that there is no cure, but there is treatment. I was living for over 20 years without drugs, but I managed through positive living. I was put on antiretroviral drugs some three years ago; my immune system and healthy living have protected me all this while.

PDA: There have been headline stories about a decline in HIV prevalence rate in Ghana lately. What accounted for this success?

BY: Intensified public education was helpful. Ironically, some people who recently came to be interviewed for positions for NAP+ upcoming projects had limited knowledge about the modes of transmission. I do not expect people to know too much detail about HIV, but they should know the basics. Further education is needed.

We should establish more anti-AIDs clubs in schools, from Junior High Schools (JHS) to tertiary institutions. The 'steam' in already existing anti-AIDS clubs in schools for the past eight to nine years is going down, due to dwindling funds for running the clubs. Something should be done about this. Also, more information on HIV should be incorporated into the school curriculum.

PDA: Would you say Ghana performed well with Millennium Development Goal 6, on HIV/AIDS?

BY: Ghana did very well in terms of the MDG goal on HIV, compared with the performance of other West African Countries.

PDA: So can we confidently say that there are fewer Ghanaians dying from HIV/AIDS nowadays?

BY: Most of the deaths are due to stress, not the HIV/AIDS itself. As I am sitting here, I am working from Monday to Friday. I have not received any allowance to support myself since October; yet, I have

been conducting a lot of interviews for people since this morning. So if I am to die it is not because of my HIV status; but because of stress.

PDA: In your opinion, how do the sustainable development goals (SDGs) address the concerns of PLHIVs?

BY: The SDGs can be summed up as the “90-90-90” target. This means that by the year 2030, 90% of PLHIV should be put on drugs; 90% should live healthy and strong; and 90% of new born babies should not be infected.

PDA: What steps is Ghana taking to achieve this goal of ‘90-90-90’?

BY: Ghana is doing very well in dealing with HIV, although there is still more room for improvement. We have to intensify our education. For instance, we do not have to wait until Junior High School before teaching sex education. It has to begin in primary school. I did a simple exercise when I visited a certain primary school in a town where I gave testimony. I gave some papers out to the pupils and asked them to write whether any of them has had sex in the past. I made sure that there was confidentiality, and that the papers were folded before the pupils passed them over to me. It turned out that eighty-five percent (85%) of the pupils had had sexual intercourse in their life time. In this situation, if you do not start this sensitization early enough i.e. at primary school, it will be a problem by Junior High School.

PDA: What do you think is the biggest challenge in the fight against HIV?

BY: Bureaucracy. Administrative delays in the running of programmes by the GAC and other stakeholders stall progress. There is also the challenge of inefficiencies in the implementation of AIDS-related programmes. Ghana has now signed a contract that allows it to draw funds from the Global Fund, which is nothing new. However, the lack of transparency in the implementation of projects and the top-down approach to project implementation make it difficult for PLHIVs at the grassroots to benefit from these funding opportunities.

PDA: How does Ghana’s strategic plan for tackling HIV impact on you?

BY: Ghana’s national strategic plan ends this year. A number of consultations have already taken place. NAP+ has already been contacted for its input on how to incorporate community system strengthening for PLHIV and key populations. I am happy to note that those things will be covered in the 2016 to 2020 national strategic plan. We need greater involvement of people living with AIDS in implementation. If we were involved in such things it will also help us.

PDA: What are Ghanaian perceptions and attitudes towards people living with HIV/AIDS like nowadays?

BY: In the past, the perception was that those who travelled outside the country were more likely to be infected with the disease. It was also thought that AIDS was a spiritual problem. Today, many people are beginning to get a better understanding and are showing some empathy.

This notwithstanding, stigmatization is still very high. For instance, after I gave a live testimony about my status at one of the communities I visited for sensitization, church members in the community refrained from joining the communion queue because I was also in the queue. This continued for three weeks. One day, a guy behind me wanted to run away but I held him and told him to stay. Many churches in Ghana still require an HIV test certificate before people are allowed to marry in the

congregation. I think that checking for your blood group and others for compatibility of couples is alright, but HIV tests should not be mandatory.

PDA: What do HIV support groups do to support themselves?

BY: We do a lot of peer education and counseling. We have developed the Models of Hope concept in clinics, with funding from the Presidential Emergency Plan for AIDS Relief (PEPFAR).⁷ We (Models of Hope) give live testimony of hope for persons who have been newly diagnosed with the disease, especially through the sharing of our experiences. We are all living examples. If I tell a newly diagnosed PLHIV that I was diagnosed about 24 years ago, he or she will calm down no matter what their emotional state. We share some of our personal experiences with our peers and visit communities where the stigma is high to do advocacy for PLHIV. We organize activities like workshops, church visits, and general advocacy wherever necessary. We also give live testimonies.

Members of the support groups meet every month to talk about positive living and to remind each other about the need to take their drugs regularly. Those who are not on the anti-retroviral drugs are also encouraged to live positively and to take care of themselves. This is the education we give to our members so as not to re-infect themselves. We also keep sensitizing ourselves on how to use condoms, and use them consistently. Since PLHIVs on medication can now safely have children, we provide counselling and advice to those who wish to give birth. Doctors are also available to offer medical services for them, and are educated on how to keep babies safe from the disease.

PDA: What is the funding situation for PLHIV and NAP+?

BY: In terms of drugs, GAC is doing well but there is still more room for improvement.... The support groups are dying because of lack of funds. Funds are also needed to sustain the operations of NAP+.

PDA: What can be done to improve funding for PLHIV and support group activities?

BY: Everybody should be involved. We need to have a pool of funding to support HIV/AIDS activities. NAP+ should lead the process. Internally generated income is one of the best ways we can use to support our activities. Some options for this for the support groups include animal rearing, kente weaving, basket weaving, fish rearing, batik tie and dye, depending on the capacities of each group. I am emphasizing support groups because they are our backbone; if they have something doing, we can say hallelujah! We at the national level can also organize something to raise money, like running transport systems. Individuals or support groups can come together to do something to yield income and share profits, or to use that income to take care of themselves and orphans and vulnerable children (OVCs).

This year is the 10th anniversary of NAP+. We have sent out a lot of proposals, some have been successful, some have not. I think all civil society organisations (CSOs) and non-governmental organisations (NGOs) should come together to support NAP+.

PDA: What is the role of NAP+ in reducing stigma?

BY: NAP+ gives a human face to the HIV situation. We do this through the use of heart-to-heart ambassadors on radio and TV. It is part of our vision to decrease the stigma. There is more room for improvement because when you go to some of the communities, it is a taboo to mention that you are HIV positive because they feel that you have disgraced the family and all that.

⁷ An initiative by the American president

PDA: What do you think needs to happen in order to reduce or totally eradicate the stigma?

BY: Education, intensive education. It should start from the grassroots and go all the way up to the national level. Even parliamentarians need this intensive education. I remember meeting some parliamentarians in Sogakope some years back when I gave live testimony. It was really enlightening to them, so I think they also need it.

PDA: Do you think people living with HIV/AIDS are getting the necessary media coverage on this issue?

BY: No. Because of the stigma, people do not feel comfortable to go public. Also, some of the media organizations are not PLHIV-friendly in the way they publish information. For instance, descriptive terms like "people who have AIDS", are not appealing. They alienate PLHIV from the media. People like me are not living with AIDS, we are HIV positive. Any description other than this is repugnant; it is misinformation.... If I am living with HIV, it does not mean that I have AIDS. If I have AIDS I cannot move. The AIDS patient does not have energy to have sex or to move around, but PLHIV move around, are strong, and work like all other healthy people. Media coverage is good, but if it misinforms and degrades people, it is not good enough.

PDA: Apart from support groups is there any other support or service that is available for PLHIVs?

BY: We get free anti-retroviral treatment (ART) services from 174 ART centres across the country. Regular lab tests for checking our statuses in labs are also covered under the free ART services. All PLHIVs are given National Health Insurance (NHIS) Cards, which makes them automatic beneficiaries of the free ART services. The GAC is leading in this endeavor.

A lot of psychosocial services are also offered by NAP+ to support PLHIVs. For instance, we have something called a Defaulter Tracking System, where those given HIV drugs are closely monitored to ensure that they keep to the routine of their medication. Those who fail to turn up for their drugs at designated periods are traced to their homes to ascertain why they have defaulted. In many cases, default tracking volunteers are able to save the lives of people who would otherwise have died from opportunistic diseases alone in their rooms, especially those who live alone. It is our duty as NAP+, and Models of Hope, to lead this process. But this programme is very costly, and requires a lot of funding. PEPFAR funded and initiated the Models of Hope programme, but the funds are now depleted. It is especially challenging in urban cities like Accra due to the sheer populations involved.

PDA: How accessible is the ART?

BY: In ART centres, the drug is given for free to all NHIS holders, as long as their cluster of differentiation 4 (CD4) count is below 300;⁸ although the WHO-recommended value for determination should be a CD4 of 500. I was diagnosed about 24 years ago but I was put on ART just about 3 years ago because my immune system was strong; and my CD4 count was above 300. Others are put on the drug soon after diagnosis because their immune system has degraded faster. It depends on each person's immune system.

⁸ CD4 cells are a type of white blood cells that helps protect the human body from infections. They alert the body's immune system about microbial intruders like viruses for response. The CD4 is the first point of attack in the human body upon HIV infection. The virus destroys these cells. It then uses the mechanism of the CD4 to replicate itself and multiply, in a process called the HIV life cycle. (See www.aids.gov/hiv-aids-basics/ for further details).

PDA: Are there any challenges at all in accessing ART?

BY: Sometimes when people want to find out their CD4, which is expected to be free, they are told the machine has broken down. Similar challenges with shortages of laboratory materials for checking viral loads exist. Those are the perennial challenges we are facing. Our viral loads are supposed to be checked once in a year, and CD4 twice in a year. But it sometimes takes up to four years before one gets access to these services! This makes it difficult to monitor the actual progression of the disease and thus manage it effectively.

Although funds remain a major challenge, good record keeping in hospitals and regular capacity building of those who handle the healthcare of PLHIV can help mitigate some of these challenges.

PDA: Which organizations are making most impact on the lives of PLHIV in Ghana?

BY: NAP+ is, of course, an essential part of the management of support groups. The Ghana AIDS Commission, UNAIDS, USAID, the World Bank, the National Aids Control Programme, FHi360, the UN system, and other NGOs are also doing well in providing funds and supporting the welfare of PLHIV. Centre for the Development of People (CEDEP) was instrumental in the formation of NAP+ and nurturing the PLHIV support groups in the mid-1990s. CEDEP initiated many of the HIV support groups. I was one of the first people to start the support groups. CEDEP asked us to start with just 15 people, but at the time people were not comfortable to come out openly. I wish to express my gratitude to PDA too, especially to Mr. Tony Dogbe, for being a great advocate for PLHIV in Ghana. In fact, Tony was very instrumental in the formation of NAP+, when he was at CEDEP.

PDA: Thank you very much for your time, and for sharing your experiences with us. We believe that publishing this will help all PLHIV and newly diagnosed PLHIV to live with hope that they can enjoy a long and healthy life. It should also provide all readers with reason to treat PLHIV with respect and to join the fight against stigma⁹.

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⁹ This interview was conducted at the office of the Ghana Network of People Living with HIV/AIDS (NAP+) in September 2015, and published on PDA website in November 2015. The initial transcript was in Pidgin English.