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Living Positively: An Inside Look at HIV Counseling and Testing in Uganda

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research article

Living Positively: An Inside Look at HIV Counseling and Testing in Uganda

—Lindsay Bergmann (Edited by Alex Miklos)

When I exit the plane outside, I am hit by two things: heat and that smell Ellis had talked about. It consists of warm, sweet dirt, a touch of petroleum, and a hint of Indian. The smell, rather than imposing, is welcoming and comforting. I have made it—a life-long dream has come true. I scan the signs and one catches my eyes, 'Linze from AMERICA'. I look around— that's got to be me!

— Journal Entry July 12th, 2009

This was quite the introduction to Africa, and certainly one that I will remember forever. After a year of long hours and endless preparation, I had finally arrived in Uganda. Bucket List Item #1: Travel to Africa—check.

With the support of an International Research Opportunities Program (IROP) grant from the University of New Hampshire, I traveled to Mbale, Uganda during the summer of 2009 to work with The AIDS Support Organization (TASO) on their Home-Based HIV Counseling and Testing program, known as HBHCT. Traveling to Africa to help with the HIV/AIDS epidemic has been an interest of mine for quite some time. My compassion for the people of Africa began when I watched an Oprah Winfrey show years back that highlighted a clinic for women with fistulas in Africa. I was appalled by the living conditions of the people and their desperate need for care. Then, as a freshman at UNH, I had the opportunity to meet Ethan Zahn, who created a soccer program called Grassroot Soccer to promote HIV/AIDS awareness in Africa. There was no escaping the emotions I had after that; I was compelled to make a difference with the HIV/AIDS epidemic plaguing Africa.



Author with TASO Mbale Manager, Mr. Kimera.

My research topic came about while I was deciding where in Africa I wanted to go. I had the choice of traveling to Botswana, a prosperous country with a shockingly high HIV rate of 23.9%, or Uganda, a relatively poor country and one of the first Sub-Saharan African countries affected by HIV, which is currently known for their remarkable success in reducing HIV rates (The United States President's Emergency Plan for AIDS Relief, 2008). Since I was in search of a more rural experience and curious to find out what exactly Uganda was doing to conquer HIV, I decided to travel to Uganda. "There's something about Africa and its people that are infectious," I was once told. I never quite knew how true that statement was until I traveled for nine grueling weeks, alone, in Eastern Uganda.

Exploring the Issue

Currently, Sub-Saharan Africa is home to 67% of the global population living with the HIV virus and 75% of global deaths related to AIDS in 2007 (UNAIDS, *Sub-Saharan Africa*, 2008). Uganda, specifically, has been battling AIDS within the country since it was first affected back in 1982 (Uganda AIDS Commission, 2006). Since then the prevalence

rate in Uganda peaked at around 18% in the early 1990's and has since declined to 5.4% (UNAIDS, *Uganda*, 2008). These statistics confirm that Uganda has demonstrated an impressive reduction in HIV/AIDS infections, a success which many countries have yet to see. According to the *New Vision*, Uganda's leading newspaper, only 21% of adults in Uganda know their HIV status (Maseruka & Manisula, 2009). In Uganda there are currently 940,000 people living with HIV and an estimated 1,200,000 orphaned children due to AIDS (UNAIDS, *Uganda*, 2008).

Human immunodeficiency virus, or HIV, is a virus that attacks a primary form of white blood cells, known as T cells, in the immune system (Centers for Disease Control [CDC], 2008). White blood cells, along with the rest of the immune system, work to fight off infection. With HIV, your body is fighting its own defense mechanism, which in turn leaves you susceptible to infection. HIV in its final stage is known as acquired immunodeficiency syndrome, or AIDS. At this point in the disease trajectory, the immune system is unable to effectively fight off any infectious cells. When someone has one or more infections, particular cancers, or extremely low T cells, a diagnosis of AIDS is made (CDC, 2008).



A field officer and the author after a long day out performing HBHCT

While in Uganda, I was able to see the impact of HIV first hand. Everyone you meet is affected in one way or another by HIV, whether it's their friend, a family member, or themselves who are positive. HIV, sadly, has become a part of the culture in Uganda. It shapes who these people are.

My role while at TASO was to observe their Home-Based HIV Counseling and Testing program, or HBHCT. HBHCT is a relatively new form of testing that occurs in the home setting of an HIV positive TASO client. For six weeks, I traveled daily by dirt bike to observe the HBHCT program and perform interviews with counselors, field officers, and clients. Because the program is so new, it had not yet been studied before at TASO and little was known about how this program is experienced by TASO staff and clients. When a client's CD4, or T cell, count falls below 250, or below 350 with a diagnosis of Tuberculosis, the client becomes eligible to begin antiretroviral therapy (ART) to help suppress the

HIV virus. The main role of HBHCT is to perform a psychosocial assessment of the client to see if he or she is eligible to start ART. Field officers, who are trained counselors, ride by dirt bike deep in to the villages where these clients live. During the psychosocial assessment, the client identifies a medicine companion to help remind them to take their medications daily for the rest of their lives. The field officer then completes an updated family census and educates the family on how to care for their loved one without contracting the virus, how to protect themselves in general from HIV, how HIV is transmitted, and the importance of testing and retesting. After this counseling session is done, the field officer offers free testing to those living in the household of the client. The testing sessions are then followed up with more counseling when the results are given and, if found positive, a referral to TASO is made.

Findings: Perceived Challenges

A preliminary analysis of the data revealed common themes in the challenges with providing HBHCT. I observed field officers having difficulties with documentation being consistent from client to client. Inaccurate record-keeping of the number of condoms distributed was an important issue, and something that TASO has been stressing because these figures affect TASO's reports. Time challenges were also a common theme in my interviews and observations, as scheduled appointments were infrequent and counseling sessions were too often cut short. This is a critical observation since the majority of all clients requested more counseling time during interviews. Also, I observed that due to the variable home conditions, basic hand washing between client visits was difficult and gloves were not consistently changed between clients. Curious whether this might be related to a lack of resources, I spoke with TASO and was informed that there were enough gloves for counselors to change them regularly. It was an individual decision to not change gloves.

During my interviews, field officers also identified barriers to providing HBHCT. Due to the dangerous driving and road conditions, bike accidents were common – so common that I actually had my own initiation to riding and crashing. The rough biking terrain, as well as journeys over an hour and a half long in the heat, leads to driver fatigue. Directions to clients' homes are often difficult to interpret. Sometimes, because of the stigma surrounding home visits, a client may give false directions. When directions are accurate, the lack of road signs can make locating a client difficult. Field officers are

required to see several clients a day. When they get held up because they can't find a home, or reach a home where there are fifteen people who wish to be tested, the quality of care the field officers can provide is compromised. Lastly, from the client's point of view, counseling and testing sessions could be made more private.

Findings: Perceived Successes

I remember working with one woman who was a client of TASO and had been abandoned by her husband and left to care for her young son. Her son was also her medicine companion. They had no home and were currently housekeeping for a friend. As you would imagine, money was very tight. However, at the end of our HBHCT session, she insisted on giving me a bag of beans. I assumed it was enough beans to feed her and her son dinner for a week. Knowing that and her situation, I struggled with accepting the offer. However, knowing the unfailingly hospitable Ugandans, I knew that to refuse her offer would be an insult. Taking her beans, though, felt just as wrong. This strong act of selflessness reflects just how grateful she and thousands of others are for the HBHCT service.

By visiting the homes of clients and speaking to them individually, I was able to see firsthand the many successes of HBHCT. For many, the cost of travel to the nearest health center that tests for HIV is unmanageable. For some, the extent of their illness may prevent them from physically being able to endure the rough and long haul to town. On top of that, once the family reaches the health center, there is still the individual cost for each person to test. With HBHCT, the field officers go directly to these people's homes and offer them free testing. To date, the HBHCT program has reached a total of 65,162 household members in Uganda (The AIDS Support Organisation [TASO]: *TASO Achievements*, 2008). That's 65,162 individuals who may never have had the opportunity to know their HIV status if it weren't for HBHCT.



Conducting interviews out in the field

Identifying a person's status is critical in fighting HIV. By learning their status, these people gain knowledge and empowerment. If positive, they can obtain care and learn how not to pass the virus. If negative, they can learn how to protect themselves from contracting the virus in the first place. This education creates awareness and sensitization. With HBHCT, the field officers educate not only the client, but also their family, about the importance of taking the medications daily and how to live and care for each other together as a family without stigma. Many people are aware of contracting the virus through sexual contact, but they are oblivious to the idea of getting it through sharing toothbrushes or sharp instruments. It is evident that clients and their families are not only fond of, but also benefit from participating in the HBHCT program.

Clearly, HBHCT is a complex program that has the potential to be an effective intervention in the HIV epidemic. With minor improvements to the current program, we can enhance not only the delivery of HBHCT, but also the expansion of the program within the Mbale District. The successes of the HBHCT program in Uganda serve as inspiration for other HIV/AIDS stricken countries. By exploring this program, it is hoped that other countries will use HBHCT as a model for improving and developing their own programs to fight HIV.

Tourist Turned Local

I have gone to the market several times buying meat that, yes, has flies all over it. It is definitely what I would call fresh meat, as the animal hangs by its feet at the market, skinned, and they just whack off a hunk of meat for you.... Fruit flies have become my friends. I sit and watch them dance on my fresh pineapple and papaya before eating it with not a care in the world!

–E-mail to home June 19th, 2009

It's safe to say that after just nine weeks abroad, living and working side by side with Ugandans, I truly became more of a local than a mere tourist. Not only did I find myself craving the nightly dishes of *matooke* (steamed green plantains), but I, too, mastered the art of eating with my hands. After many failed attempts and much laughter by the local children, I even learned to speak basic phrases in not only Luganda, but Lugisu, Lugwere, and Ateso—several of the local tribal languages in Eastern Uganda.



That being said, the transition from a tourist to a local was no easy thing. It entailed washing my dirt-stained laundry by hand, countless dark nights due to power cuts, and waterless showers at the most inconvenient of times. The hardest thing I had trouble adjusting to, however, was the change of pace from the way I usually live life in America. As my roommate in Uganda explained, as Westerners, we are a culture of “to do,” meaning we feel we must constantly be doing something in order to feel satisfied and worthwhile. In Africa, they are a culture of “to be.” Simply being is acceptable and is a way of life. Patience truly *is* a virtue.

Enjoying the local craft markets in Jinja, Uganda

Until We Meet Again

In school, we are taught that nursing is both an art and a science; that it is about the human connection and the ability to feel for one another. The experience of immersing myself in another country's culture provided an opportunity to connect unlike any other. Whether it is the smell of sweet dirt and petroleum, the sound of my boda (motorcycle) driver calling me at home in the US to tell me, “Eh, Lindsay, you've been lost. Have you forgotten me?”, or the sight of the school children, dressed in their uniforms, running to greet me after work, I know that Uganda will always be a part of me. As I continue onward with my nursing practice, I will always keep the memories of this experience with me. I plan to return to Uganda once I graduate and volunteer at a local health center in order to give back to a community that has given so much to me.

This has been the trip of a lifetime. I feel that I have grown so much as an individual and have experienced so much. Dr. Lugalla was right—Africa is infectious. It's in my blood now. It will always be a part of me...It's so hard to say goodbye.
– Journal Entry August 20th, 2009

I would like to thank the following for all of their help and support along the way: Mr. Ellis Woodward, without his generosity and love for Africa, this trip would not have been possible; Dr. Georgeann Murphy and the rest of the Hamel Center for Undergraduate Research for believing in me since day one when I entered their office as a curious sophomore with big dreams; Dr. Gene Harkless, my faculty mentor, for the countless hours of guidance and support; Mr. Denis Medeyi, my foreign mentor, for welcoming me in to his country; Dr. Joe Lugalla, for sharing his plethora of HIV research and knowledge; Dr. Carol Williams-Barnard, my honors mentor; and a huge thanks to all of the staff at TASO who have become such dear friends of mine. To my friends and family, thank you for all of your support and encouragement along the way! Weebale nnyo. Thank you very much!

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Author Bio

Lindsay Bergmann, from West Chesterfield, New Hampshire, is a senior nursing student in the Honors in Major program at the University of New Hampshire. She performed this research, which forms the basis of her honors thesis, in summer 2009 with financial support from the International Research Opportunities Program (IROP). Lindsay has long held a desire to help those struggling with severely insufficient healthcare treatment, especially those suffering from the HIV/AIDS epidemic in Sub-Saharan Africa. While experiencing vast cultural differences and a craving for the familiar, Lindsay's time in Uganda was among the most meaningful experiences of her life. She discovered that the program at the focus of her research, an AIDS treatment and counseling service, possesses the potential to be very effective. She also learned that performing research is a complex process and she harbors a newfound appreciation for all research endeavors. After Lindsay graduates in May 2010 with a B.S. in nursing, she plans a return to Uganda to do volunteer work and hopes to become a certified nurse midwife for those who lack proper obstetrical/gynecological healthcare.

Mentor Bio

Gene Harkless, DNSC, ARNP, is an associate professor in the Department of Nursing. A family nurse practitioner who has taught at the University of New Hampshire since 1985, Dr. Harkless is a frequent mentor who enjoys working with students as they take on international endeavors. "For past IROPers, it has been life-changing. They create a whole new lens through which to see the world," she says. As UNH faculty mentor to Lindsay Bergmann, Dr. Harkless recognizes that Lindsay's work with TASO, an indigenous HIV/AIDS service organization, ran the gamut of emotions from dispiriting heartbreak to jubilant triumph. And though they perennially struggle with inadequate healthcare, Dr. Harkless appreciates that the Ugandan people's generosity sees no bounds, as they welcomed Lindsay with robust warmth.