

# PROLONGING DESPAIR: ANTIRETROVIRALS WITHOUT SOCIAL SUPPORT IN HIV-POSITIVE YOUTH

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*The purpose of this narrative is to recognize the lack of social supports for youth born with HIV and to discuss the ramifications and possible mediators of this deficiency. With two lines of antiretrovirals (ARVs) available in urban Tanzania at no cost, many children born with HIV have the resources necessary to survive; however, their survival does not depend solely on physical wellness. Without social supports, free ARVs do not always achieve improved quality of life for youth. This narrative follows the story of Lilly, a girl whose life was prolonged by ARVs but taken by intolerable emotional turmoil. The lifesaving supports needed for youth like Lilly are discussed, including family-based education, supportive counseling groups and a system for referral to these services. Note: Names have been changed for individuals cited in this paper other than Theresa Kaijage. Author does use real name for WAMATA.*

*"Kinyozi hajinyoi na akijinyoa hujikata."*

*Translation: "The barber doesn't cut his own hair and if he does he cuts himself." - Swahili proverb*

## Introduction

AIDS, death, poverty, and turmoil are commonly associated with Africa. The following is a true story of these terrors, a story that may elicit feelings of sorrow or anger. Still, as in most stories of turmoil in Africa, a profound message can be found. This article is about a needed change for a vulnerable population. Its purpose is to give life to the story of a girl who died trying to tell it, and to help interested parties prevent recurrences of her story in the future. Descriptions of the following interconnected environmental factors precede the narrative: my role and purpose, the narrative's setting, and my colleague for this case.

## My Role and Purpose

Tanzania is a place of beautifully diverse scenery, fascinating local languages and rich history. The weather, like the dancing, vacillates between fierce and placid. Tanzania's largest city, Dar es Salaam, is a coastal metropolis, where traditional ways of life intermix with modern and international customs, creating an epicenter of cultural learning. This fascinating city was my campus for the final field placement of my master's degree in social work. My concentration

focused on leadership, policy and administration, though my classes and fieldwork included significant clinical learning as well.

I previously volunteered to manage program development and construction at a community school in Zambia for eight months. During that stint I visited a total of five African countries. Consequently, at the time of my placement in Tanzania I was familiar with many of the sights and sounds of sub-Saharan Africa; however, I had not received academic credit for my work, represented the social work profession or worked specifically with people living with HIV/AIDS, until I lived in Tanzania. Additionally, with an estimated 2007 adult HIV prevalence rate of 6.2% of the population (UNAIDS, 2008), Tanzania had a significantly lower HIV/AIDS rate than any other African country I had visited. I began to understand the spectrum of differences in HIV/AIDS rates between countries and to identify additional HIV/AIDS resources needed in sub-Saharan Africa. This was a location and population with significant need, where I could learn about the AIDS epidemic and make a meaningful contribution.

Resources are limited in Dar es Salaam. However, the people I served and socialized

with were eager to learn modern skills and facts that inform practice. My role in Tanzania reflected both the resource limitations of the area and my Tanzanian colleagues' eagerness to learn. Initially I was scheduled to assist in an administrative capacity at an HIV/AIDS clinic named Walio Katika Mapambano Na AIDS Tanzania (WAMATA), meaning *people in the fight against AIDS in Tanzania*. WAMATA provides comprehensive HIV/AIDS prevention and care, focusing on the areas of home-based care, treatment of opportunistic infections, and support groups. While the majority of my time involved working on fundraising and program development at WAMATA, my internship was diversified to include additional tasks and work with other HIV/AIDS agencies.

Dr. Theresa Kaijage, the founder of WAMATA and my internship supervisor, is a charismatic connector of people and agencies. Through her connections and generosity I was introduced to other projects needing support and training for an enthusiastic staff. After several weeks of experimenting with various roles at agencies, my internship was structured to include regular observation, participation, and project leading at WAMATA, an HIV/AIDS counseling unit in a private hospital, and the Tanzanian Social Work Association, among others. The following narrative focuses on one experience in the HIV/AIDS counseling unit of a private hospital. It is representative of numerous stories from the other previously mentioned internship settings, where I encountered similar narratives and learning lessons.

#### **Mlalakua Hospital**

Mlalakua Hospital is a mid-range private hospital serving mostly middle- to high-income Tanzanians. Clients pay fees, though they are significantly reduced from the fees of elite hospitals serving wealthy domestic and international clients. Mlalakua Hospital medical professionals are generally knowledgeable and experienced, but often lack the resources required for providing the best possible care for clients. As is frequently depicted in movies and commercials involving medical care in the developing world, Mlalakua Hospital has

narrow hallways overfilled with sick and injured people. Some need more immediate care than what is available. Several of my most disturbing and haunting experiences in Tanzania included a walk down the hospital hallway, which doubled as a waiting room. I would squeeze between crowded benches lining the corridor, stopping between each bench to step aside for medical personnel and patients requiring emergency care. These patients would be rushed through the crowd along with their stretchers, IVs, and other medical devices. Often times the sounds of crying children would echo from the patient's rooms, intensifying the already desperate mood in the hallway.

The HIV/AIDS unit operates separately but similarly to the other hospital departments. Mlalakua Hospital's HIV/AIDS services are well-rounded and include testing, counseling, prescriptions, provision of medications, emergency HIV/AIDS care, treatment of opportunistic infections, and education. Much of the HIV/AIDS funding is acquired from the government through international aid, though clients still pay an appointment fee of approximately \$6.50 for each visit. Patients receiving medications for AIDS visit the clinic at least 12 times per year, at a total cost of at least \$78. This represents 17.7% of the 2008 average Tanzanian's yearly income of \$440 (Bureau of African Affairs, 2010). Additional costs may be incurred for special lab tests or medications, especially when clients show symptoms of opportunistic infections.

#### **Nurse Afya**

After discussing the goals of my internship with the human resources director of the hospital, I was introduced to Nurse Afya, the head nurse in the HIV/AIDS unit. Nurse Afya is a nurse by training, but a counselor and case manager by job description. Her duties include counseling individuals and families, educating HIV-positive clients about the illness, encouraging adherence to medical advice, and dispensing medications. While most of her client care occurs in her office, at times she attends to HIV-positive patients in the Intensive Care Unit. These clients typically enter the hospital not knowing they are HIV-

positive and are diagnosed after medical personnel order a test based on their symptoms of opportunistic infections. Nurse Afya conducts crisis counseling for these patients, while occasionally assisting with their medical care as well.

Curious about the discrepancy between Nurse Afya's training as a nurse and her role as a counselor, I inquired about the hospital's staffing and organizational structure. Affecting Nurse Afya's role was the lack of trained social workers or counselors. No one at the hospital had social work training and only several had certificates in counseling. With a degree in nursing and a three-month evening program certificate in counseling, Nurse Afya had the same level of training as the other hospital counselors. As I advocated for these professional fields with the human resources director, he admitted counselors and social workers were needed at the facility. Still, he and other administrators did not understand exactly what role those workers would fulfill or how it would improve services. In my discussions with Nurse Afya, the answers became obvious.

Nurse Afya admitted to me that she often felt unqualified for the work she was doing and wanted advanced clinical social work training. Her fierce ambition to continue her education always impressed me. When textbooks were available, she read in her free time in order to advance her skills. She tried several times to return to the university for a social work degree; however, she could not afford to leave her job and her work schedule was too demanding to permit both.

Due to these factors, as we structured my internship with the hospital, it seemed my time would be most effective in assisting and training Nurse Afya. Since she did not have a firm grasp of the difference between administrative social work (my concentration) and direct practice, Nurse Afya asked for my assistance with counseling. Nervous that I might be working beyond my professional scope, I sought advice from previous professors and internship supervisors. They all assured me my training and education in direct practice was more than sufficient in this situation and significantly beyond what was currently

available at Mlalakua Hospital. Additionally, experienced stateside professionals were willing to assist me throughout the semester. Ultimately, Nurse Afya and I discussed ethical conduct, social work roles, relationship-building strategies, and specific counseling techniques relevant to her clients. When time permitted I facilitated debriefing sessions after difficult counseling situations. We attempted to set aside the first 30 minutes of the workday to discuss cases. Later in the day patients were waiting in a queue in the hallway. Still, we would lock the door and carve out 15 or 20 minutes to have "morning" tea with *chapati* (a modified version of Indian flatbread), at noon or later, while discussing counseling techniques.

During sessions I was of little help. Appointments were conducted primarily in Swahili. Although Nurse Afya, fluent in English, would translate excerpts of the discussion, I was usually unsure of the session's general direction. Additionally, as a nurse, she was required to explain HIV/AIDS and instruct patients regarding their healthcare, something I was unqualified to participate in. I was most helpful during the few fleeting moments of calm in the office, when we would discuss cases. Still, when we met with a client in a difficult situation, Nurse Afya would translate consistently and ask me for advice during the session. One example of this is the tragic but informative story of Lilly.

### **Lilly's Story**

Lilly, 17, entered the hospital with opportunistic infections, though she did not describe her condition that way. Her condition was generally obvious due to the dark spots on her skin, weakness and shakiness, and the presence of typical opportunistic infections. Due to her young resilient body, and despite the indications, she did not appear as ill as her blood work later proved her to be. She was immediately placed in the Intensive Care Unit for treatment. Though she was timid with the nurses, when asked directly, she finally shared her HIV-positive status with one of them. At that point, Nurse Afya visited the client to assist in developing a plan of action. Nurse Afya's shift was almost over and Lilly was

scheduled to remain at the hospital overnight. Therefore, after discussing appropriate care for Lilly's immediate medical needs, Nurse Afya made an appointment to see her the next morning, when I would be present.

According to my first impression, Lilly was a calm and timid girl who showed much respect for authority. She listened intently and spoke softly. She displayed her coherence and sincerity by greeting me warmly in English before sitting down. Though she walked holding onto shelves and file cabinets to support her weakening body, she looked comfortable and strong sitting in a chair. Her faded pink and white outfit seemed mildly worn and outdated, but well cared for. She looked like a fairly typical young client. Unfairly, after hearing about Lilly's hesitance with the nurses, I had expected her to present as confused and unkempt. Instead Lilly's maturity and respectful demeanor immediately dismantled my preconceived notions. I soon identified the source of her maturity; her story reflected a life lived well beyond 17 years.

Over the next 75 minutes, Lilly explained her story to us, taking breaks for Nurse Afya to translate, ask clarifying questions and explain medical aspects of HIV/AIDS. This seemed to be the first time Lilly had felt comfortable enough, or possibly desperate enough, to share her entire story with someone. During our meeting, Lilly shared secrets and feelings she had apparently never shared before; most notably, she explained how she discontinued the first line of antiretrovirals (ARVs) because in her intense emotional anguish, she wanted to die. Lilly was resolute about her plan and had been unwaveringly committed to it for several months. It seemed her embarrassment, fear, isolation, and physical fragility were too overwhelming, and she believed death was her only escape. Without further discussion of the medication, Nurse Afya and I both silently recognized that Lilly had probably developed a resistance to the first line of ARVs; however, since two lines of ARVs are commonly available in Tanzania, we still believed there was hope. Unfortunately, whether from forgetfulness or embarrassment, Lilly had withheld an important detail of her story. Lilly, silent and determined, had actually stopped

taking her ARVs on two separate occasions—first and second-line. At the time of our meeting, she was probably resistant to both. We discovered this two days later, and months too late.

Lilly began her story chronologically, starting with her acquisition of HIV. Her mother passed on the illness either during birth or during breast-feeding in infancy. Lilly tested positive around her third birthday, after both her parents died from AIDS. Before passing away, her mother birthed a second HIV-positive child, Lilly's younger brother Edmond. Lilly and Edmond moved in with their Aunt Agnes and Uncle Prosper, who were embarrassed by their illness, often lying about the cause of their parents' deaths. Though both were infected, Lilly and Edmond did not even discuss HIV with each other.

According to Lilly, AIDS and sex were taboo subjects within this new family. I believed that easily, knowing many of my clients had encountered similar circumstances. Despite the high HIV prevalence rate in Tanzania, sex is not generally freely discussed in Tanzanian households. Youth in Tanzania often learn about sex in their classrooms, through experience, or through stories and rumors from peers. Through these processes, Lilly learned that HIV can be transmitted through sex and since sex is a taboo subject, her HIV was something to be ashamed of. She learned that she must try to avoid infecting others with HIV, while her peers must try to avoid becoming infected with HIV. She wondered why she was burdened with the consequences for someone else's mistakes. Throughout her childhood and adolescence, her brother Edmond was the only person her age that she knew had HIV. Lilly recounted a peer asking her if she was HIV-positive because of the spots on her skin. Students teased and avoided her after she answered with a timid "no." From then on, some of the students suspected Lilly to be HIV-positive and ostracized her. This further discouraged her from sharing her status.

During our conversation Lilly expressed mild anger and confusion toward her biological parents. She seemed to be holding back, only allowing herself a hint of emotion. Yet the deep

anguish in her eyes belied her attempt. Since the death of her parents was never fully explained to her, she was left wondering which parent contracted the disease first and from whom. Were her parents happy with their relationship? What did they know about the prevention of HIV transmission? Did they actually want to have children? Did they utilize prenatal care and education to try to prevent transmission to Lilly and her brother? As Lilly grew older and understood more about the transmission of HIV, complex layers of questions developed. Meanwhile, her growing understanding of stigma related to AIDS deepened her inner turmoil and embarrassment over the disease. At this point in her story, I began to understand how Lilly's emotional isolation became so extreme that she wanted her life to end.

As a young teen, Lilly's CD4 (T-cell) count dropped below 200, and she was prescribed ARVs. This happened just as ARVs were becoming available in Tanzania. Without them Lilly would have been especially vulnerable to opportunistic infections and would have been at the end of her life. Lilly started receiving ARVs from her local government hospital, where the medication was free. (Unlike Mlalakua Hospital, the government clinic visit is free, in addition to the free medication.) While free services entice many impoverished Tanzanians, there are significant drawbacks to government clinics: most notably, long wait times and limited medication availability. Due to high demand, most patients wait several hours to a full day at government clinics before being seen. When they finally meet with medical personnel, needed medications for opportunistic infections are often unavailable. If patients do not have funds to procure the medications at a separate pharmacy, they must take additional time away from their responsibilities to wait at the clinic another day. Working patients usually miss an entire day of work every month to visit the clinic. Further, employees and students may find it difficult to have their absences excused without disclosing their status.

Confidentiality is minimal while waiting in long lines for hours. While the actual visit is confidential, waiting areas are typically not

confidential, creating an obvious waiting space used only by people who are procuring ARVs. Though this was true at Mlalakua Hospital as well, the wait at Mlalakua was usually under one hour and there were significantly fewer clients. Many youth are so embarrassed by the stigma of waiting in a long line with little confidentiality that they refuse to obtain medications at a free clinic. While Lilly said little about this process, it was probably a contributing factor in her decision to stop taking ARVs.

When Lilly began treatment at the government hospital, she was issued a standard national blue card for recording her medical history in case she moved or switched hospitals. At first, one of Lilly's guardians accompanied her during each monthly office visit. Together they would receive medical advice and medications. Lilly's guardians helped her remember to take her medication at the designated times in the morning and evening. Around age 15 Lilly expressed her desire to visit the clinic alone. Lilly's guardians allowed her to go alone, but verbally reminded her about appointments during the first few months. Over time they ceased reminding her to procure medications and to take them twice daily, deeming her old enough to do it herself. While Lilly was old enough to remember, she was not motivated enough to go to appointments. Secretly she stopped visiting the clinic and stopped taking the medications regularly. When she was motivated she would. When she felt depressed and helpless, she would not. Emotionally drained, Lilly finally stopped taking the medications altogether and hoped to die.

Eventually Aunt Agnes questioned Lilly's medication adherence and asked to see her blue card. At this time Lilly's behavior was exposed. Information on the blue card ended abruptly three months earlier. No office visits were recorded since that time, nor had any medication been dispensed. While Aunt Agnes was unsure how to support Lilly's wellness, she wanted to help. Without significant emotional displays or discussions, Aunt Agnes returned to the clinic with Lilly hoping to encourage her to reinstate her regular treatment schedule. Using a system of trial

and error the government clinic nurse determined that Lilly had developed a resistance to the first line of ARVs. By the time the story was relayed to us Lilly understood the importance of medication adherence, especially regarding the second (and last in Tanzania) line of ARVs; however, it was unclear whether she had understood the importance of adherence when she began treatment with second-line ARVs, and subsequently discontinued it.

This is when I began to understand the significance of the appointment fee and commitment to quality service at Mlalakua Hospital. While Nurse Afya does not have her preferred measure of training, she works in a supportive environment where the caseload is low enough for staff to feel invested in individual patients' treatment plans. For every new patient or new treatment plan, Nurse Afya conducts three appointments over the course of three weeks to discuss a checklist of information a patient must understand for the best treatment outcomes. Most importantly, the discussion includes medication adherence and prevention of transmission, including mother-to-child transmission when applicable. When beginning a new treatment regime, patients are fully informed of the repercussions of failure to follow the plan during treatment. They are consequently able to make independent, informed decisions about their health. Further, they can be advocates in their communities, helping to reduce the stigmatization and isolation of other people living with HIV/AIDS.

Though I was unaware of the procedures in place at Lilly's original government clinic, I had spoken with HIV/AIDS patients using other Tanzanian facilities; many of them make poor health decisions due to a lack of accurate information about the consequences. Lilly's clinic, overloaded with patients, may not have fully explained the importance of following her treatment plan, or may have only explained it to Aunt Agnes. Those issues, combined with her developmental level, could have prevented her from understanding the seriousness of discontinuing her medication. Lilly specifically stated she discontinued medication with the intent of dying; however, many youths in the

United States express this same intent in a "cry for help," an upset episode when a detrimental (often life-threatening) act is carried out but does not ultimately end in death. This can allow friends and adults to recognize the severity of the youth's pain and encourage the youth to seek help. For Lilly there was no going back. Discontinuing her medication for a month, a week, or even just a day, could prevent it from ever working again.

By the end of our meeting, Lilly had agreed to take two measures for her health: 1) attempt resuming medication (Nurse Afya and I were not yet aware that Lilly had discontinued both lines of ARVs) and 2) bring us her blue card the following day, Friday. Reading Lilly's blue card would allow Nurse Afya to gather more information about Lilly's discontinuation of medication and possibilities for increasing her CD4 count and overall health in the future. On the following day, Lilly was too weak to bring the blue card from her hospital bed, so her aunt brought the card. During this surprise meeting with Aunt Agnes, more information about Lilly's condition was revealed. Of utmost importance was the fact that Lilly had in fact discontinued medication on two separate occasions—first and second-line. This was evident from the gaps in service on her blue card. She stopped taking medication two to three months earlier and was likely to be resistant. Given this information Nurse Afya and I knew Lilly could attempt second-line medications again, but they probably would not work.

In addition to this heartbreaking news, Aunt Agnes recounted an unsettling story about Lilly's development and struggle with HIV. The story occurred about one year previously when Aunt Agnes visited a friend, leaving Lilly alone at the house. When Aunt Agnes returned she searched the house for Lilly, stopping near Lilly's bedroom when she heard a boy's voice inside. Through a knothole in the old wooden door, Aunt Agnes saw Lilly performing oral sex on a teenage boy who was unfamiliar to Aunt Agnes. To avoid a more embarrassing situation, Aunt Agnes largely ignored their behavior, listening and peering in occasionally to ensure their sexual acts did not progress. After the boy left, Aunt Agnes lectured Lilly

about the dangers of intercourse and foreplay. It seems the lecture was primarily an attempt to shame Lilly away from future sexual acts due to her illness. She was told definitively that she could never have sex because she would give AIDS to her partner.

I was impressed with Aunt Agnes' ability to discuss sex openly. Either Aunt Agnes was disregarding her family's customary avoidance of sensitive subjects or Lilly had exaggerated about the avoidance. While Aunt Agnes' interaction with Lilly was based in openness, concern for others, and knowledge of HIV/AIDS, it did not encourage Lilly to share her story, ask questions, or improve communication with her caregiver. The conversation shamed Lilly, leaving her to wonder alone "Why me?" She was angry and embarrassed about suffering through an illness that could be transferred in the most personal of ways. An earlier prevention-based conversation focused on sex, not just AIDS, may have been more helpful. It would have involved less shame and stigma. It may have even allowed for a new subject of discussion in the household, giving Lilly and Edmond more support in their struggles with HIV.

As it was, Lilly was far too embarrassed to share her HIV status with a boyfriend and knew having sex meant risking secretly passing on the deadly disease she inherited. With the standard risks of lesser sexually transmitted infections and pregnancy countering peer pressure and hormone changes, youth generally face difficult decisions regarding their sexuality. Lilly faced those same pressures, magnified immensely by knowing sex could be a matter of life or death for her partner. The culture in urban Tanzania is not very progressive regarding women's roles and sexual rights. For most young female clients I met with, the decisions to have sex and to use protection were made by the man alone, without input from the woman. This could make it harder for Lilly to speak up in a dating relationship, and could make her feel like she was forbidden from dating at all. This conflict deepened her emotional turmoil and further isolated her from her peers, during a developmental stage when sex and relationships were a common topic of

discussion. For Lilly, the most painful aspects of the illness seemed to be her inability to prevent it and her lack of emotional support from peers and mentors.

After hearing this story, Nurse Afya invited Aunt Agnes and Lilly to visit us again early the next week, then thanked and excused Aunt Agnes. I was unavailable Monday but returned on Tuesday, anxious to see Lilly or at least hear about her case. My enthusiasm soon waned as Nurse Afya relayed to me the news she received Monday morning. I sat motionless in surprise and sadness as I learned that Lilly had passed away on Saturday afternoon. Her death was a quiet but rapid fade into stillness. The doctors knew it was untreated AIDS. None of the emergency care available could save her. Even if it could, without access to a third line of ARVs, her life still would have ended too soon.

With the news of Lilly's death, Nurse Afya and I expressed our sadness about our dashed hopes for her future. There would be no third attempt at initiating ARV treatment. There would be no lingering hope of a happy and healthy future for Lilly. Nor would there be referrals to support and education groups, something I had quietly resolved to advocate for. In the morbid way of many social service workers, Nurse Afya joked about Lilly's death. "She wanted to die and we wanted her to live, so I guess she won," Nurse Afya said, covering her disappointment with an awkward laugh. I echoed her sad and gentle laugh, trying to decide if there really was some joy to be found in that statement. "You're right, Lilly won," I muttered.

### **Implications**

While I regret my inability to say goodbye to Lilly, I have written this article as a memorial. Lilly's narrative is intended to raise awareness and inform practice. Not a single person in Lilly's social or resource network had the knowledge, enthusiasm, and courage Lilly needed to help her find an outlet for her emotional struggle. Lilly was one of the first to suffer in this way. There will be many more otherwise healthy children born with HIV who will not develop AIDS until their teen years. Since Lilly survived without ARVs until age

13 and started taking them almost immediately when they became available in Tanzania, she was one of the oldest in a growing generation of teenagers who contracted HIV from their mothers. Many of this generation were orphaned in childhood, their parents dying before ARVs were discovered and available. Lilly is not the only one who silently suffered the pain of losing her parents, was ostracized from her peers, became increasingly medically fragile, and was raised in a setting that prohibited emotional expression regarding AIDS.

Despite the growth of this population of youth, there is little recognition of the difficulties they face. Doubtless, others were praising the miracle of ARVs while I was mourning the loss of Lilly, someone who had access to this medication. This life-sustaining miracle drug is now available to roughly 30% of Tanzanians who need it (World Health Organization, UNAIDS, & Unicef, 2008). Yet, after hearing Lilly's story, I had mixed feelings about ARVs. They helped Lilly live a longer life, which only seemed to supply her with more misery. If ARVs can be consistently provided concurrently with emotional and social supports, they will be more helpful for youth like Lilly. Thankfully, Nurse Afya and I benefited from Lilly's story. We gained a deeper understanding of the tribulations facing the estimated 140,000 infected Tanzanians under age 15 (UNAIDS, 2008). Lilly's story and other personal experiences have helped me identify three social services that will likely improve outcomes for youth like Lilly: family-based education, support groups, and referral.

Family-based HIV/AIDS education is invaluable for families raising youth who are HIV-positive, especially when the youth have been orphaned and the caregivers do not have HIV. Not infected with HIV, Lilly's caregivers not only avoided the subject of HIV/AIDS, they did not even understand many of the physical and emotional struggles she faced. I question whether they had a thorough medical understanding of the disease. Conversely, families can be empowered to support their own HIV-positive youth through family-based education, a service that can be provided in a variety of forms. The most cost-effective form

would be a group classroom setting for many families to learn together. This could be offered at the clinic, or when resources are limited, at a local NGO. Unfortunately, a classroom setting would only benefit the families who are motivated to attend, not the families who are likely to need it most. A more comprehensive method would involve asking at least one family member to participate in the initial clinic meetings with youth. Both individuals could learn together about HIV's transmission, course, and treatments. If the youth develops questions or struggles with the illness, the family member would be equipped with the tools to support them. This type of education could have aided Aunt Agnes in becoming aware of the emotions and pressures Lilly faced. It may have helped Aunt Agnes feel comfortable and confident enough to initiate childhood discussions about AIDS and, later, discussions about sex.

Similarly, support groups can help youth feel more comfortable discussing sensitive subjects and can potentially encourage them to initiate dialogue with their families about their feelings, pressures, and decisions. Lilly's foremost complaint was, quietly but consistently, her lack of social support. She did not feel comfortable asking her friends and family members about AIDS, and did not want to reach beyond that to teachers, neighbors, and extended family. With peers insulting her and her family avoiding the discussion of sensitive subjects, Lilly found no support in her struggle.

Since HIV-positive youth have different struggles than their adult counterparts, support groups for only HIV-positive youth would be beneficial. Simply meeting other youth who have faced similar ridicule, emotions, medical treatments, and sexual confusion can decrease feelings of loneliness and increase coping skills. Support groups have the potential to help youth build friendships, open lines of communication, become leaders in decreasing stigma, and initiate peer outreach programs. These groups can be a healthy medium for providing youth-friendly sexual education. If youth choose to explore sex, they can seek advice in an open and honest environment where questions are encouraged and guidance and resources are

provided. Some difficulty may be experienced initially in building these groups due to the embarrassment and stigma HIV-positive teens face. Socialized to avoid disclosing their status, there will be struggles with discussing HIV, even with the other group members being HIV-positive. Improving systems of referral can help mitigate this.

Youth like Lilly can easily fall through the cracks when there is no system for referral to social services. Due to the stigma of the disease, they may need encouragement to visit an HIV/AIDS service provider. Further, they may struggle to find transportation money, and are likely to be limited to visiting the site closest to their home. This increases the opportunity for their friends and neighbors to see them entering an HIV/AIDS related facility, and subsequently decreases their ability to keep their status private. For these reasons, support groups and family-based education are best provided at the hospital or clinic itself, where confidentiality can be maintained more thoroughly. When that is impossible based on resource limitations, the clinic's counselors, social workers, and nurses can initiate the development of partnerships with local social service agencies that can provide these services. Mlalakua Hospital should refer their clients elsewhere at this time due to a shortage of counseling staff and confidential space. Since youth often need extra encouragement to pursue services outside their regular clinic, it may be valuable to help them arrange an individual and confidential meeting with one of the partner agency's staff members before they participate in a support group. With a gradual introduction to the agency's staff, members, goals and methods, youth are more likely to feel comfortable and eventually integrate into the education or support group.

The government and large nonprofits may best address the issue of referral. Currently Tanzania has a standard procedure for Voluntary Counseling and Testing (VCT), determined by the government and carried out by individual clinics. VCT is the system through which individuals are tested for HIV. The government sets standards for medical personnel in performing the HIV blood test as well as pre- and post-test counseling. These

government procedures were followed consistently at the agencies I worked with. A referral process could be included as a standard part of VCT. After testing, those who are found to be HIV-positive would be either immediately or at a future appointment, referred to family-based education and support groups provided at the testing clinic or a nearby social services agency. While some clinics currently practice this type of referral, an explanation and description of the referral process from the government may help enforce the process. For now, clinics may independently decide to develop partnerships and refer HIV-positive clients and their families to supportive services. Each clinic has the opportunity to give someone like Lilly the tools needed to thrive.

As for my contribution to social services at Mlalakua Hospital, I provided Nurse Afya with the tools for taking the first steps toward family-based education, support groups, and referral. During our conversation, Lilly had contemplated attending an education group about HIV for infected, affected or just interested youth. The group is at WAMATA, within walking distance from Mlalakua Hospital. While Lilly was never able to attend the group, I provided Nurse Afya with the contact information for a WAMATA counselor, who happily agreed to meet with future referrals. Additionally, my supervisor met with Nurse Afya, strengthening the connection between Mlalakua Hospital and WAMATA.

Two weeks before leaving Dar es Salaam, I met an American clinical social worker interested in volunteering in the HIV/AIDS field. After I introduced her to Nurse Afya, they began counseling together. This was similar to the arrangement Nurse Afya and I had, except that the new volunteer's clinical skills built on and furthered the concepts I had previously introduced. Due to the partnership I established with the human resources manager of Mlalakua, the new volunteer was in a position to advocate for developing social work positions there. Lastly, my professors donated and transported social work textbooks to Dar es Salaam, helping Nurse Afya and others improve their skills. While my contributions were small, they may serve as

steps toward a healthier and well-supported generation of HIV-positive youth.

Consideration of the emotional needs of HIV positive Tanzanian youth is needed in direct practice and administration. Preexisting agencies should develop programs dedicated to this issue, and entire organizations can focus on it as well. Lives will be saved, and every local and international staff or volunteer can make the difference for someone. Simply being aware of the situation and taking small steps to build understanding can make a dramatic impact on a life like Lilly's.

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Stephanie Pulliam, LMSW, is a Conservatorship Worker with the Texas State Department of Family and Protective Services. Comments regarding this article can be sent to: [SJPulliam@gmail.com](mailto:SJPulliam@gmail.com)

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