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A Lesson in HIV/AIDS and the Human Experience: Inspired Toward Nursing by Volunteering with the Kenya Network of Women with AIDS

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emphasizes family, friendship and community, I felt that this was an excellent model for bringing much needed health care to a group of women who would normally be uncomfortable receiving advice from an “outsider.” Another way in which the nurses have built trust in the community is through doing home visits, as a free and caring gesture to families with very limited resources. I was able to participate in these visits one afternoon. Wilson, the four-year-old pictured here, has a congenital disability similar to cerebral palsy. He has never had a complete neurological workup because his family does not have the financial resources to travel and visit a specialist. Wilson lives in a one-room cinderblock home with dirt floor and palm leaf thatched roof, in a rural area where supportive care for children with disabilities is nonexistent. The nurse does a brief physical assessment to assess Wilson’s neurological, cognitive, and nutritional status, and talks with his mother about strategies for keeping him healthy. For example, in this picture he is sitting in a padded high chair, but he needs to have a strap system put in place to keep him upright in the chair since he has poor muscular control. Because of the relationship of trust that is developing between Wilson, his mother and the nurse, Wilson has the benefit of limited developmental support and he can be brought to the hospital if his condition deteriorates.

The time I spent with Wilson was one of my best yet most heartbreaking experiences in Honduras. I spoke to him in Spanish, and he recognizes his own name although he does not seem to understand anything else. He has such an pleasant temperament, and although he cannot speak he was very engaged and stared at my face, smiling, and reaching out to touch me. As I interacted with him, it hurt to see the health disparity between his situation and that of a child in the U.S. Here, Wilson would have a formal diagnosis for his condition, he would be taken to physical and occupational therapy sessions in little wheelchair, and he would receive developmental and educational support even if his family was poor. But those things are inconceivable in Honduras, and

Wilson is blessed to have a loving mother and the watchful eyes of the nurse. I wished I could bring him home with me and give him the care he needs to live the healthiest life possible, but I just had to give the child a kiss on the cheek and wave “adios” as he started to cry.

My experiences in Honduras with the women’s health care program and the home visits now serve as a case study on trust building between nurses and patients in the community. This presents and open door for me to do future investigation in this area; I am currently writing two related papers on this topic, and I hope to tie my findings in with a broader study for my senior project.

As I embarked on my trip to Nairobi, Kenya to volunteer with the Kenya Network of Women With AIDS (KENWA), I knew it would be an intense two and a half months. However, at that time, I could not imagine what I can now vividly picture in my mind after seeing, hearing, and experiencing HIV/AIDS in the slums of Kenya. The following quote was in the back of my mind as I traveled and recorded what I saw and did there: “Just as an observation is a form of control, so too is the process of writing and representing what has been observed.” So as not to further control the process of observation and recounting events, I am presenting excerpts of my journals that I kept during my time in Kenya, all of which propelled me on the path to a nursing career.

Excerpt 1
Addis Ababa airport
The night before I left, I watched a TV show about HIV/AIDS. In this TV show, a man from Sierra Leone went to Zambia to work as an orderly in the hospital. He dealt with dead adults, dead children, broken families, despair, and loss. If I see, in person, even half of what I witnessed on the documentary, my heart will break, although I am very emotionally together. As of tomorrow, my life will be devoted to those I meet dealing with AIDS in some way in Kenya.
If I wanted to be a doctor, this is most likely what I would do. I would be here as a doctor actually providing free or affordable medical care. Maybe I’d join Doctors Without Borders, but I am not a doctor – nor do I plan to be one. But I hope these roles get filled. We all have our place in life.

Excerpt 2
I met my first AIDS patients today as well as some orphans. Many of the people working with or volunteering for KENWA are HIV positive, but they are very healthy compared to the people they help. Today, I spent several hours with Grace. She is a 3 year-old girl who has Tuberculosis. Her mother just died of AIDS two weeks ago, and she is now alone. Luckily, she is HIV negative herself, but she is very small and malnourished for her age. She’s about the size of a two-year-old, and I am not exaggerating. While she is being treated for her Tuberculosis, she is staying at the KENWA clinic. Today, we drove her to get her treatment, and the hospital was overcrowded especially in the waiting areas. We went to the pediatric ward, where all the mothers were there with their children. The atmosphere wasn’t too bad, but it is such a clear difference from hospitals in the United States. I am not saying it is completely bad here, because they do very well, but appearances and processes are very different.

After taking Grace back to KENWA, she looked so sad – sad in the deepest possible way. Her face was downcast, and her eyes would meet mine and then look away. I spent time with her just trying to play and get her to at least smile and also saying “Unataku kucheka?” or “You want to laugh?” Finally, she started playing and even smiled. A long time later, she finally laughed, and it made me so happy to see her and eyes light up. Also, apparently, she is not at all familiar with milk,
which tells me that she did not grow up drinking it although it would normally be a staple for a child here too. Now is the beginning for her, and I hope it goes well.

Also today, I met a boy named Joseph. He has Tuberculosis and is HIV positive. Additionally he has heart problems, which complicate all of his treatments. However, he just had a blood transfusion and is doing very well. I sat with him for a good while, but I don’t think he speaks much English, so we just sat in comfortable silence.

Today was quite a day, and very little actually happened. I can’t imagine what it will be like during field visits and when I meet all the orphans at the sites.

Excerpt 3

As we drove along to the various places in the slums, I thought of all sorts of poetic ways to explain what I was experiencing. Then, I realized that no words and nothing I could say could explain what I saw today. And, in fact, it would almost be wrong to even try -- couldn't possibly do it justice. So, for the sake of you following my trip, here is a tiny overview of what we did -- minus my emotional responses.

Today was my first day in the field. We left and drove over an hour to Thika. There are slums there where all the buildings are made of mud and wood or corrugated metal. It is the typical image you would think of for Africa -- lots of barefoot children running around in old clothes, laughing and waving to the white person. (I am exhausted with this generalization. I didn’t know what to paint a picture for you.) KENWA has a drop-in center there, and we went there first to drop off the ARV drugs that are distributed there once a week or so. Then, the rest of us and a few local volunteers got in the van and drove down to the orphanage another hour away. We went to visit a boy and “check on his head.” I didn’t know what that meant until I saw his head. I don’t feel like giving full details of what it looked like would help, but, needless to say, we took him back with us to go to the hospital in Nairobi. (He has herpes breaking out on his chest and a terrible dermatological infection on his head.) Luckily, he will be fine (although he is HIV positive), but he was in pain and was very sad. That typical sad and disoriented face will always follow me...and I have only been exposed to this hopeless expression for two days now.

On the way back to the drop-in center from the orphanage, we stopped at various houses to drop off various supplies like beans, corn, rice, vaseline, flour, and bandages. I went in to visit one client (there are the people like the social workers who keep track of certain people). I walked into the deep house that was barely lit and found him on a bed in the back room. He had a bad eye infection that was maybe cancerous. It looked pretty serious though -- sort of like red bulges on the eye itself, which were visible even when he closed his eyes. He said it was painful. He is also paralyzed on one side. He has to be supported to walk. We were heading back for him next Friday to take him to the hospital for his eyes. He is also being treated with ARV drugs at least and does have his family. As I walked out, his sister greeted me (in Kiswahili) and then offered me an avocado.

I also met an HIV positive woman who is the caretaker for two positive orphans. Such is how things work here. Even those suffering take care of others, especially children, who are in need.

We stopped along the way several times and jumped out of the van to give out boxes of condoms.

We also picked up a family on our way back that needed a ride. Their little girl was sick, and they were going to the hospital. She ended up sitting next to me, and she immediately leaned her head on me and put her hand on my arm. I put my hand on hers. Eventually, I put my arm around her too.

We got back to the center, and I was given food. I ate my avocado and gave some parts out to 3 other people.

We drove back to Nairobi and took the boy to our center to be looked at by the doctor there. I think he didn’t have to go to the hospital, which is good.

I gave Grace, the little girl I met yesterday something to color today. I also made her laugh today. If only I spoke the language she spoke, Kamba, it would be better. But she smiled when she saw me today...and that was good. I will visit her tomorrow too before going to the field to see if she colored anything. Luckily, some Kiswahili is interchangeable with Kamba, so we can at least somewhat communicate.

I am sort of glad to be alone here in my thoughts in taking all this in. However, I know that sometimes people need to hear about things. Don’t expect strong emotional outbursts here, but at least you know what I am doing.

By the way, I learned the word “kutapika” today...“to vomit!” because one woman volunteer had to get out of the van twice along the way and kutapika due to the bumpy roads.

Excerpt 4

Yesterday was good and very different! I went to the field again but this time to a slum called “Mathare.” It was one of the most filthy and garbage-heap place I have ever seen. It was almost like the people were living on top of a trash dump. We walked down to the drop-in center, and there were no home visits this time. Instead, I worked in the kitchen preparing all the food to give out to people who came into the center. In the kitchen, I learned to make ugali in a huge jiko (pot/oven). Ugali is when you mix the rice and water, and then you add more milk until it is extremely thick, stirring the whole time. It ends up really thick, and you can just pick it up and eat it.

I stirred it as it cooked with a long wooden stick/spoon that was about a yard or a meter long. I wasn’t really sure how I did, but they all kept saying (while eating) that it tasted “swetted.” I just smiled and one of them, “Well, how do you make it not sweet?” One replied, “Oh, well....maybe not sweet. Maybe ummm....not cooked properly.” SO, the truth comes out!!! It wasn’t cooked properly, but I tried, and they were being nice!! Maybe next time. I also helped pick out the bad beans before cooking them. It took forever, but we were all sitting there just talking and picking beans and chatting.

At the end of the day, we left in the KENWA van back to the main office. On the way out of Mathare, I saw two men on the ground fighting, and one was about to punch the other. Then, we turned the corner and left. Such is life there, I suppose. Back at the headquarters, I visited the kids I am now friends with and another woman named Leah who is a patient. I also helped wash all the dishes from a meal there. AND, prize of the year for me, I was the first American EVER to wash dishes at KENWA. In fact, they even asked if I knew how! I said, “But other Americans have been here, right?” And they said, “Yeah, but they never helped with the kitchen stuff.” So, I made history. I played with the kids some more, and we were playing with these cars I brought.

Tomorrow, I have to be at the office at 7 a.m., because I am leaving to the field again to a place called Nyeri. But, Nyeri is really far away...like 200 km or something. So, we leave VERY early so we can spend the whole day there. I will be exhausted. Aons, Sunday, I am going out with another woman from KENWA to distribute toys to several towns around Nairobi and to Thika (where I was on my first day in the field).

As you can tell, it was an intense day yesterday. I’m glad to be here and doing this, but the work is very challenging at times. I can’t explain WHY I am glad -- because it isn’t about making myself feel good by being here. It is something deeper than that which makes it worthwhile and brings me some semblance of happiness.

Steve Kanja, the boy we brought into the center, said to me yesterday, “I want to be a black American.” He was explaining to me why his English was so good. But what is an appropriate response for such a statement? Am I allowed to take him back with me and let him be a black American? I must be careful not to become too connected -- or it will rip my heart out when I leave.

The doctor was telling me about a woman
who has a CD4 count of 20. (He says that normal is somewhere between 400 and 2,000.) They are trying to get her to eat healthy and stay active before they start her on the ARV drugs. I don’t completely understand why they would wait to give drugs, but I guess they want using the ARV’s to be sustainable by giving them to people whose bodies are healthy enough to process them and use them adequately. Another girl and I were told to be moved to isolation, because she got chicken pox. If she stays with the others, she would possibly infect all of them. Her moving opened up a bed for Steve Kanja, who is now doing much better and is much brighter. He has also made friends with Joseph, and they seem to be enjoying each other’s company. Grace is still there and looks better every day. She’s eating better and actually plays with the toys I brought. I saw a new kind of food yesterday, which is a dietary supplement used for people who have been malnourished and need concentrated nutrients. It was a bar that had many of the needed nutrients and vitamins concentrated in one place. It’s a really good idea.

Excerpt 5

Today was the most intense day so far. I thought a woman was dying in my arms. I don’t think I could describe all the thoughts going through my head, because I was even unsure of what was going on – both medically for her and emotionally and psychologically.

Today, I was in Thika. I watched a group therapy and education session about opportunistic infections and how to treat them. After that meeting, the ARV’s were distributed to all the people there, and each person brought a card with them that aid “ART” for antiretroviral treatment. It is filled out each time they receive drugs to keep track, and if they miss too many weeks, then they are no longer allowed to receive them. After that, I went into the field with the others. We stopped at one house with a woman. She seemed weak, although fairly healthy overall. She didn’t look malnourished or sick really, but she couldn’t stand on her own. Maybe muscle wasting is the cause of that, but I’m not sure. From her place, we went to a place just outside of Thika. As we drove in on the extremely bumpy roads, there were finally buildings all made of gray cinder blocks. The town was very flat and had a gray hue due to the construction materials used for all the houses.

We passed through the small central part of the town and arrived where houses were arbitrarily scattered. We stopped at a small square house made of wood. We went in and found the worst state of a person that I have ever seen. She was just laying there on her bed and moaning and crying. Her eyes were very faraway looking - although when she saw me, she did actually say “hi.” She lived in a small room with her mother and sister, who care for her, although I only saw one bed, so I guess the other 2 sleep on the dirt floor maybe. They have very little money and very little food. The room was actually given to them by “a good samaritan” as it was explained to me. And, the woman hadn’t been eating lately either, so she was very, very weak. We determined that she had to be taken to the hospital immediately. But someone heated water first, and we undressed her and bathed her there in her bed first so she could arrive clean at the hospital to help prevent further infection.

Then, the nurse sat her up while I got the Vaseline, which they use as general body lotion. I started rubbing it on her. I did her right arm and then her left arm. I knelt in front of her and began doing her chest and legs when her head sort of started going backwards and her body stiffened. She started convulsing as I put on the Vaseline and the nurse held her. The nurse, Mary, lowered the woman back to the bed. As she shook, I lifted her feet onto the bed and covered her body with the blanket and watched her eyes roll back into her head. I held the woman’s eyes with her fingers and kept repeating her name and touching her forehead. Another woman, Lucy, had her hand on the woman’s arm. I had my hand on her leg. Her sister was standing in the corner covering her face and crying. The woman stopped convulsing, and she was still alive.

We then dressed her and carried her to the van. Her sister sat by her head, and her mom sat by her legs for the bumpy ride there. When we got to the hospital, Lucy ran in and brought a wheelchair. I stabilized the wheelchair as they lifted her in, and then I helped turn her around and put her into it. I unlocked the brakes, and Lucy started to push the chair. The woman held my hand, so I ran along with the chair as we entered.

Then, I learned more about hospitals here again (third hospital here so far). We went in and joined the group of people surrounding room #27: the examination room. There is no Emergency room to take her to -- and when we left, it looked like she would just have to wait her turn behind all those people who had their own sisters and mothers. I hope they got her in faster though. People all around were looking at her as she still moaned and continued to collapse forward in her chair without support.

This woman used to be healthy.

Excerpt 6

Also last week, I had an entire cultural experience with the family I am living with: Mercy, Edward, and their children and extended family. Mercy’s aunt’s dowry was only half-paid at her time of marriage, so the rest needed to be paid soon in order to avoid “a curse.” If the grandfather dies before the dowry is paid, then a curse occurs. However, they all say that they don’t REALLY believe that, because they are Christians now. They say that it is more about tradition and the fact that the family needs this money to pay hospital bills for the grandfather, who is now sick. But regardless of the reasons, it was an excuse to bring the family together, and I was invited. First, all forty or so of us sat and ate together. Eventually the main people involved (the older family members) went into the house to discuss prices that would need to be paid to cover the full dowry. In the past, it would have been an actual cow, but now, instead, they pay the price of a cow as the dowry.

Then, on Friday, I went to a drop-in center where I hadn’t been yet called Maraga. It seemed different there, but I think I had an important experience. I rode in the van with those going to get their ARV’s at the local hospital. I learned what it is like to sit and wait for hours through the multi-step process of getting weighed, seeing a nurse. Granted, I wasn’t actually waiting for life-saving/life-prolonging drugs, but I waited with everyone else, talked to some people, and made some children smile.

I am beginning to realize that I need to stay here longer. I don’t have enough days with KENWA, and I don’t have enough days for everything else. I have become so passionate about this work, these people, and the challenges and rewards here. I will definitely be back. Maybe after I graduate.

Excerpt 7

We left late for Thika yesterday, so I spent some time in the rescue center first. Before we left, I went and played with Grace again and with the other boy, Joseph, and the small son of a worker at KENWA. I made a paper airplane and entertained them for about an hour just by throwing it at Grace. Then, it would hit her and bounce off, and she would jump up and down laughing and spin in a circle. (And compare THIS to when I first arrived, and she was just lying in bed not very responsive!) Now, she even talks and says “hi” and “byby” to me, although she speaks Akamba and Swahili. I speak some Swahili sometimes to her though.

I also found out today that she does not yet know that her mother is dead. Her mom died about a month ago, and she hasn’t been told yet. That is just one more thing for her to deal with coming soon, although her health is improving a lot.

We went to Thika finally, and I went out into the field. I asked one of the people there how that woman was that we took to the hospital last week – the one that was so incredibly sick and almost died with us. This one man said, “Oh, she kicked the bucket. That same day that we
just had Tuberculosis. It hit me pretty hard actually. It turns out her family is actually in Thika, but just recently, the rest of the children were left with others while the drunkard father comes and goes (according to KENWA workers). Again, I really hope that things can turn for her. She has already improved so much in the past month and a half. I want her to have a chance at a happy and long life. I want that for all the orphans I meet, especially the HIV positive ones.

As we left one woman’s house, she was saying how bad it was of her to have visitors without offering hot food. We told her it was nice to just sit together, talk, and visit. People that we visit are so warm and generous. They always invite us in for homes and garden and try to help by speaking some English or in clear Swahili. I will never forget how generous and genuine everyone has been here. It should be an inspiration to us all.

We visited another family that is doing really well and living positively. The parents are HIV positive, but they are both on ARV’s and said, “Why would we die now?” They have three children too who do not know that the parents have HIV. They fear the stigma and fear that it may affect the children in school.

Excerpt 9

If you read the earlier entries, you’ll read about Joseph, who I went to pick up from the hospital with KENWA. He had been transfused then and was improving. He stayed at KENWA at the main rescue center until about three weeks ago. He had become very sick and was transfused for the third time in three months; only this time, the transfusion was not helping. I came back from traveling to find him in a state unlike I have ever seen. People here have an amazing strength in the healing power of God, and that can cause some problems in the healing from the medical community’s perspective.

We also went to the smallest house I have ever seen. I think prison cells are larger than this room. I would estimate that it was maybe 7x7 feet squared. Inside, there was one chair and then a woman lying on mats on the floor. The woman in the chair cares for the woman on the floor, and she also cares for eight orphans in addition to her own children. In all, she has about 15 children that she provides for. I can not imagine the determination and selflessness that it would take.

We visited another woman who said she is a client with many problems. Apparently, she suddenly became paralyzed last year. Now, she can not move around on her own, but she has two sons who have finished high school and help her a lot. She had to be bathed and changed, so I assisted. She had used the bathroom in a basin under her chair, that had to be cleaned. We left clean clothes after everything. I can’t imagine the mental state that comes along with needing such care. I’m sure she must be used to it by now, but it must be quite difficult. She was telling us how happy she was with her sons and they accept her as she is. I think she must be very lucky to have them, because so often, the family seems to abandon them. She also has hopes of regaining her mobility, and I was told two stories of other women with the same problem who were able to walk later. I hope that happens for her too.

In Thika, we went to visit and deliver food to the man with the eye infection. He was supposed to be picked up by us weeks ago to be taken to the hospital, but there was some problem with transportation, so he had not yet gone. This time when we arrived, the door was locked. Unfortunately, sometimes that is the best a caretaker can do when they must leave the person home alone. We were able to get to the window and talk to him at least, and we passed food through the window for him. I was also told that his family does not have good care of him, and they do not have enough food for the family.

The big shock to me of late is the information that Grace is HIV positive. I don’t know why everyone kept telling me she was HIV negative, but they did— all this time, I thought she...
Nicaragua

Stephanie Kleven

As a Fulbright Scholar in Nicaragua, outstanding new experiences were a near daily occurrence. Some held more weight, left a deeper footprint in my memory; but they were all significant. The first time I witnessed a birth, however, takes the cake.

It left me breathless, and raised important personal questions for me, as well as questions about health care delivery and ethics.

As part of my public health project in Nicaragua, I was visiting the birthing ward of the only public hospital in the entire region of Matagalpa. Its six pre-partum beds were full, as always, and more women waited in the halls, one laboring uncomfortably and exposed, on a gurney. The young male obstetrician seemed brute, insolent, jaded. You're here to observe, not judge, I reminded myself. Besides, the doctor's work conditions were far from ideal. Each woman lay alone, separated by precariously hung curtains, laboring on small plastic beds. A lone fetal heart monitor comprised the bulk of modern technology at work.

Like many hospitals in Nicaragua, extremely limited space and privacy prevents women from being accompanied by a family member or birth partner and scarce resources inhibit the hospital from employing sufficient staff to care for all their patients. The result? Exhausted, overworked doctors and nurses, and poor outcomes for the laboring women. It was early January when I visited and the doctor informed me that they had already lost 3 babies of the 70 or so that had been born—an abnormally high percentage, even for that hospital.

Soon after arriving, with little time to absorb my overwhelmingly foreign surroundings, one of the women began pushing. As though he'd done it a million times before, the doctor half-heartedly sprung into action. He told the laboring mother to walk to the delivery room. She awkwardly, painfully, waddled the thirty feet and hoisted herself onto the bed. For two more eternal minutes, she pushed, alone. Her moans echoed in the eerie silence of the room; the doctor and nurse offered minimal encouragement. I wanted to hold her hand, to tell her that she was doing well, to offer some token of support, but knew instinctually that it simply was not my place. In my mind I was cheering, "You can do it! Be brave! Keep going!"—hoping that my thoughts would somehow show on my face, be transmitted to her through some unspoken feminine language. Maybe it was only my imagination; but for a long, suspended moment, our eyes met, and something told me that she heard me.

It was all happening so quickly, and seemed so brutal—a far cry from the handholding, Lamaze-breathing births on the Discovery Channel that make even the most unsentimental person feel warm and fuzzy. This felt like raw, unforgiving nature at work. I couldn't help but imagine the stark contrast of what her birthing experience might have been like had she decided to stay in her community and give birth at home with a community midwife, sister or friend. What if circumstances had been different and fate had offered her a North American life like mine? What if it were me laboring on that table? Injustice has a sneaky way of making me appreciate the role circumstance plays in our lives.

Moments later the doctor began preparing for an episiotomy, leaving no doubt that time was of the essence. Beds needed to be cleared! While injecting the local anesthetic, the doctor informed me that he breaks the bag of waters at five centimeters, no matter what and performs episiotomies on almost every single woman. I have seen many