

January 2006

The Children's Rights Centre has been dedicating more and more attention to the issue of Pediatric HIV, especially in the context of the National Antiretroviral Rollout. It's very difficult to get solid statistics on the number of children living with HIV in SA right now: studies cite prevalence rates ranging from 5.4% to 12%, with a total number of 300,000 to 400,000 children ages 0-14. Studies suggest that 89% of children born in Africa with HIV will die before the age of 3 without treatment. Only 7,000 children are able to access antiretroviral medication nationwide.

The work of the CRC on this topic ranges from advocacy and lobbying to information sharing and networking. My work has fallen under the project heading of "Child Friendly Healthcare Services," which allows me to use photodocumentary methodology to help monitor and evaluate healthcare at various sites, as well as collaboratively produce treatment literacy materials for patients in care. Treatment literacy is a word that gets thrown around quite a bit without consistent definition: to me, it means any materials (print, audio) that educate a child about an illness and its medical care.

When we first started this project, my work consisted mainly of monitoring. I visited sites in Durban, Marionhill, Khayelitsha, shadowed doctors as they consulted patients, and interviewed pediatric patients and their caregivers. Though the sites ranged from urban to rural, public to private, the same issues appeared again and again. Broadly, the clinicians, counselors, and often caregivers were extremely reluctant to speak to their children about HIV to the point where I met 13 year old girls who had been told their entire lives they had "asthma" or "diabetes."

Children were seldom addressed directly by the clinicians during consultations, were permitted to ask no questions, and received no formal or informal education at the clinic or at home about HIV or antiretroviral therapy.

This was the point at which we decided to focus on developing age-appropriate treatment literacy materials for caregivers and clinicians to use with children. We wanted to use a very collaborative methodology, to enable children already in care, their families, and their clinicians to share their knowledge and stories with other children in similar circumstances. We envision the final product to be a book appropriate for ages 5-12 containing photos, narratives, artwork, and spaces for children to write, draw, and record personal and medical information.

During the month I spent in Khayelitsha last year with Doctors Without

Borders, I had the opportunity to meet with many different groups. I worked at a creche ages 0-5 for children with HIV, made photos and interviewed children and caregivers. I met with a group of twelve mothers who were raising HIV-positive children and held a series of focus groups to discuss their experiences. I met regularly with a group of twelve 15-22 year old youth active in the Treatment Action Campaign to talk about the psychosocial implications of HIV, especially in the context of friendships and romantic relationships. I shadowed doctors and nurses at three HIV clinics in the township and made images in waiting rooms and during consultations.

The majority of these images and narratives were lost in the theft last May, but some assorted prints have been slowly steadily trickling in from project participants. The options for massive scanning of all these images are limited, and I'm hesitant to mail them overseas as they're the only remaining prints in existence. Some of them will be useful for producing treatment literacy materials here, and I will bring all of the prints back with me to the US and at that time discuss the best way to archive/use them.

Most recently, I've spent all of December and much of January in Lusikisiki, a small town about an hour inland from the East Coast. It's a desperately poor area, with 70% unemployment and HIV prevalence rates of more than 30%. Doctors Without Borders provides HIV services at 13 different clinics scattered across the region. I visited almost all of these clinics (some a 90-minute car ride from town on mud roads) and developed relationships with several families that extended into home visits. Specifically, I worked closely with three young people (9-11) who are living openly with HIV and have received some information about their status. Together we made photos and I conducted interviews with them and their families based on the photos.

My time this month in Durban has been spent drafting the text of the treatment literacy materials, using interviews and adapting adult-level resource materials, and meeting with a volunteer graphic designer to create some preliminary layouts. I plan to make 1-2 more site visits during February and March, to the Red Cross Children's Hospital in Cape Town and to St. Appollinaris hospital in the Eastern Cape. The remainder of my time will be spent finalizing, publishing, and distributing the book.

10 March 2006

The past month has been one of the busiest so far. I've spent several weekends commuting back and forth between Durban and Lusikisiki (about a 4 hour drive under reasonable circumstances, and about 3 harrowing hours by minibus taxi), following-up with the families and health care workers I met there in December. I've also been working closely with a graphic designer on the layout and design of the pediatric treatment literacy materials - recently christened the Living Positively Handbook (for Children with HIV). It's coming along quickly, and I'm looking forward to the end of next month when I can return to the various project sites with a finalized draft for the participants to approve.

Due to the scarcity of treatment literacy materials for children, we were excited when a group of early childhood development workers in a neighboring country offered to send us a CD with worksheets and stories they're using to teach children about HIV. When it arrived, however, we became less enthusiastic. One workbook contained coloring book images of a baby coughing up blood ("Can you color baby's blood red?"), a dying parent in a bed ("If your parents died from HIV, what would you remember about them?"), and two frightened children being chased by a pack of faceless monsters ("Very bad things can happen to orphans. List some of those things in the space provided.") Some sections were simply bizarre. A worksheet with a herd of cows, some very thin and some fat, asks "Can you circle the cows with AIDS? Cut out all the cows with AIDS and put them on one side of the fence. Put the healthy cows on the other side."

On a small level, these attitudes about educating young people are unfortunate. On a larger scale, they're dangerous. The arrival of the worksheets coincided with the release of a new LoveLife media campaign in South Africa. LoveLife is a government funded organization tasked with raising awareness and prevention messages about HIV among children aged 15-29, the group with the highest new infection rates. The new campaign features billboard ads on the theme of "HIV loves..." including "HIV loves skin on skin" and "HIV loves your daughter" and "HIV loves players" and "HIV loves women getting pregnant to prove their womanhood." Images are nearly-abstract silhouettes: of a pregnant woman's body, three pairs of feet sticking out of a blanket at the foot of a bed, etc. These negative messages about people who become infected by HIV - that they are promiscuous, that they are somehow "asking for it," have become the target of several protests by NGO's and PLWA's. At worst they are offensive, at best they are simple scare tactics, but under no circumstances are they educational or do they foster positive attitudes about people living with HIV.

These are just a few of the many examples of how HIV is (mis)represented in educational materials and media in South Africa. It's easy to identify the mistakes, but difficult to blaze a better

trail. We find ourselves considering topics we never would have imagined: How do you define sexual assault so that a girlchild under 10 can understand it, can name it if it has happened to her, but not live in fear of it if it hasn't? How do you explain resistance to a 5-year old in danger of defaulting her second-line regimen? How do you explain the difference between HIV and AIDS to a 7-year old? How do you support a 9-year old who has received threats of violence against her family because of her status? Very seldom do we have good answers, but we're getting better at connecting with people who do: mothers, grandmothers, pediatric patients, doctors, nurses.

9 May 2006

One of the most valuable parts of this fellowship for me has been the flexibility it extends to fellows to do interdisciplinary work in various fields that can inform and support our documentary projects. A

year ago I became involved with McCord hospital, a state-subsidized semi-private paediatric antiretroviral treatment site in suburban Durban. In addition to founding a playgroup for patients on Mondays and Wednesdays as part of my work at the CRC, I volunteered to help with a research study the program was undertaking.

Nearly 10 months of evenings, weekends, and holidays later, our paper is ready for publication. If and when "Preliminary Outcomes of a Paediatric Antiretroviral Cohort in KwaZulu Natal, South Africa" appears in a scientific journal, it will become only the fourth paper in published literature to describe how children are treated with HAART in all of Africa. None of these papers document more than 100 children on treatment. This number pales in comparison to the amount of studies published on paediatric HAART programs in the Western world, a discrepancy which becomes truly alarming when viewed in light of paediatric infection rates in SubSaharan Africa. Number of children living with HIV in America: 9,300. In Sub-Saharan Africa: 3 million. The Sub-Saharan Africa number would easily be in the tens of millions if the children born with HIV here weren't dying at such an accelerated rate (80% by the age of 3).

This work has given me a chance to increase my clinical knowledge of paediatric HIV infection and management a hundredfold, make valuable connections with clinicians and patients, all of which has informed my documentary work on treatment literacy. Additionally, it has given me a chance to reflect on the nature of scientific study as documentation, and the need for amplifying the voices of underserved populations within scientific communities.

At a PEPFAR conference last year, I stood up and asked a pharmaceutical representative about progress on developing fixed-dose combinations of anti-retroviral medications for paediatric use. Fixed-dose combinations, or "FDC's" are combinations of different medications in a single capsule. Instead of 12 pills a day, the patient must take 1 or 2, an advance which has been attributed to increased adherence rates in communities where they're available. However, paediatric formulations do not exist. The representative gave what I imagine sounded like a reasonable answer to him: "There really isn't a market for them."

A Doctors Without Borders poster displays a similar complaint. A young doctor (an acquaintance from my time spent in Khayelitsha) stares out from behind these words: "The TB drugs I'm prescribing were invented before I was born. And the only thing that has changed in TB diagnosis over the past 120 years is the level of the doctor's frustration." At the bottom of the page, we are informed that TB incidence rates in Khayelitsha are approximately 1112/100,000 per year. In Lusikisiki, a small town on the Eastern Cape, HIV-positive patient support groups

have formed a choir and recorded a CD. One of the catchiest songs lists (in Xhosa) all the different types of TB that a microscope cannot detect - TB meningitis, TB of the eye - and for which other diagnostic methods are not available. It is disconcerting to find oneself singing this song in the shower.

I arrived here as a documentarian with the intention of using photography within communities to amplify the voices of the underrepresented, the underserved. The longer I spend here, the more I become convinced of the necessity to find methodologies that allow these communities to be heard not just by the general population of the western world, but specifically within scientific circles. Having spent a good deal of time around medical professionals in South Africa and in America, I am wary of the difficulties of introducing such a "soft science" as photography and narration to such formulaic minds, but I believe we as documentarians owe it to the populations we work with, somehow, to try.