



Examining the Evidence: The Impact of Housing on HIV Prevention and Care

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“Yo ban nou selman sa nou bezwen pou kenbe mouri, men pa ase pou nou viv.”

Following my opening remarks on Wednesday, Shawn Lang commented on my passion for this summit. Well, now I will tell you the truth. I find research largely tedious. Talk of algorithms, data sets, regression analysis and the like, frankly bores me. So, as much as I believe in this event, I have to trick myself into paying attention. Unless, of course, you throw some sex in your presentation like TJ Ghose did. Otherwise, my Blackberry will quickly find its way into my hand.

So what I decided to do this time was to bring three women with me -- at least in my imagination. Now before any of you get the wrong idea, I'd like to introduce them to you. The first is Esther Boucicault. This April, she will be the recipient of the fourth Keith Cylar International AIDS Activist Award. She is the first HIV-positive person in Haiti to come out on radio and television about her HIV status.

I visited Esther last fall in St. Marc, where she runs a small AIDS service organization that she created in her own community. Esther runs the only psycho-social case management program in all of Haiti. She is able to do so because she receives a grant from a Canadian foundation that she uses to pay stipends to 65 people living with HIV to provide peer to peer outreach and case management and to pay a psychologist to meet with patients one day a week.

With access to Global Fund and PEPFAR dollars, Haiti is reasonably well off when it comes to HIV medications. But not one dime of these funds can be used for psycho-social services, much less housing. As a consequence, in all of Haiti, the poorest country in the western hemisphere, the only housing support for people living with AIDS and HIV is one privately operated six-bed shelter in Port of Prince.

It was in describing her frustration at the focus on drugs into bodies coupled with a total disregard for the need for nutrition, transportation, housing, and psycho-social supports, much less employment opportunities that would allow people to be self-sufficient, that Esther said these words: “Yo ban nou selman sa nou bezwen pou kenbe mouri, men pa ase pou nou viv.” They translate: “They give us only what we need to keep from dying, but not what we need to live.”

A few weeks after I got back from my trip to Haiti, I visited with Sandra Banda, a woman we were hosting from Zambia while on a speaking tour here in the United States. Sandra is a person living with AIDS and works for a Zambian AIDS service organization. She told me that the lack of housing was the biggest barrier to getting people onto HAART therapy. I asked if there was any housing assistance available. Sandra responded with a snort. “Housing assistance? Ha! We don't even have assistance for food.”

“Actually,” she said, “I shouldn't exaggerate. We do have a small food program, but you really have to need it.” “How do they determine need,” I asked. “They have to smell the hunger,” she

said. She then described how over a two week period, the inspector would make three surprise visits to the applicant's home. If the inspector found any food whatsoever during one of these inspections, the applicant was deemed ineligible. And if the applicant qualifies? The household receives a food supplement of one pound of beans and a pound of rice every month.

The third woman is Cheryl. Cheryl came to my office in early December the year before last. She was at the time a patient in one of our health centers. She suffers from severe bi-polar disorder and is chronically chemically dependent. Cheryl had been attending the program almost daily for nearly a year. During that time, she had started taking her psychotropic medications again, and she reported that she was not only adherent, but that she had not smoked crack in over three months.

Notwithstanding these accomplishments, Cheryl, who regularly attended a Bible study I lead every Sunday morning, wanted to share with me her incredible anxiety and ask that I pray with her. She was sleeping under an abandoned tractor trailer. Cheryl, you see, had a t-cell count too high, though not by much, to be eligible for HIV/AIDS housing support from New York City's HIV/AIDS Services Administration. Just the day before, she had her quarterly blood draw and was anxious about the lab results. Having explained everything to me, she said, "I want you to pray that my t-cells fall low enough so I can get a place to live before winter gets too cold. I don't think I can keep it together if I have to keep living the way I'm living now."

Sure enough, Cheryl got her lab results the next week. Her t-cells continued to remain impossibly high. A few days later, she stopped coming to the program, and we haven't seen her since.

So as I have listened to the various presentations, I've pretended that each of these three women was sitting beside me and imagined how they would respond.

I'm sure all three of my friends would have loved Shirlene's opening speech. But they probably would have been confounded by the policy discussion that followed. Forget about the acronyms. The debate over the priority placed on health care versus housing as a human right would probably be incomprehensible to women coming from countries that offer neither to people who are poor and fairly disposable.

I wondered if Cheryl would think that we did her a disservice by working so hard to maintain her health, encourage her adherence to her psychotropic medication, and supporting her efforts at recovery from crack, since these effectively became barriers to housing.

I think all three women would have been fascinated by the panel on Housing Status and HIV Risk. In Haiti, the safest survival option for a homeless girl is to become a domestic in someone's home. But that really doesn't protect from violence and sexual violence. Esther introduced me a 14 year old girl, who, at the age of twelve had been raped by the man in the household where she was a domestic, then thrown out of the house and raped again by the man who next took her in, with the result that she was infected with HIV.

Cheryl, I know, could have vouched for Elise Riley's presentation on the role of sexual violence in homelessness and as a barrier to housing as well. Violence, and particularly sexual violence, is what drove Cheryl to sleep alone, hidden under a tractor trailer.

I'm sure Esther would have been fascinated by TJ's report on brothel-based sex workers in India. She took me to the brothel district in St. Marc, where her teams do outreach with sex workers. The Catholic parochial school marks the boundary to the strip that looks a little like East Broadway here in Baltimore, only much shabbier, bar alternating with brothel one after another for over half a mile. The district is called "Nich Myel La" – the bee hive.

What was missing for me in that panel was an opportunity to have a real dialogue about the seeming incongruence between sexual violence and women using sex to empower themselves. I don't know where I would fall on the many issues that conversation would raise. But what I do know is that we haven't spent nearly enough time looking at, not just sexual violence, but the larger issue of the "disempoweredness" of women and girls in both the pandemic of AIDS and that of homelessness.

I was glad that Carol Wilkins raised this issue again this morning. The implication, I think, is that housing as an intervention works only if it is truly a threshold to empowerment, something that is not always the case. -- And speaking of violence, Richard Cho's presentation on incarceration and homelessness reminded me of the research I saw in 1970's showing the correlation between childhood violence, and particularly sexual violence experienced by both boys and girls, and incarceration.

Richard Wolitski's presentation of the impact of stigma would have certainly resonated with Esther, Sandra and Cheryl. They would have very much appreciated his emphasis on the damage of internalized stigma. Whether it is homelessness, addiction, AIDS or just plain old-fashioned homophobia, we all know stigma kills. But we need the research to prove how deadly it is.

I can't underscore the significance of either the H&H study or the CHHP study. It's so incredible to be able to say that CHHP's random assignment structure shows a clear causal impact: Case management and house result in significantly better health and lower costs for people with chronic conditions.

I told David Holtgrave yesterday that these studies have given me my response to New York City Speaker Christine Quinn the next time she expresses her fear that housing homeless people with HIV might set a dangerous precedent requiring housing for homeless people with other chronic conditions such as diabetes, cancer, and heart disease. "Do it," I'll say. "And the faster the better if you want to save New York City a huge chunk of money and improve health in New York at the same time."

I know people would love for H&H to be simpler. Wouldn't it be great if the spread between the control group and the intervention group had been greater? I'm sure all of the results would have proved significant in both prevention and care, much in the direction that we all expected. But what has made this so complicated is that so many people in both groups actually got housed, by hook or by crook....and isn't that a wonderful thing.

It doesn't surprise me a bit that an attendee would ask if the research subjects got to keep their housing when the study ended. All too often research is focused solely on getting the researcher's questions answered, with only the minimally required attention to the impact on the subjects. Researchers, don't take offense. Often on the advocacy side we are similarly more interested in finding the consumer who can tell the most compelling story, sometimes without appreciating what is really happening in that individual's life.

And speaking of the research subjects, I was blown away by the study participant panel. Claude, Theo, Mary, and Keith, you all blew me away. And Deborah is my sidekick on the NAHC board, so I knew what we were in for. Mary, I can't imagine how bad it must have felt when you were told you weren't getting a housing voucher. I thought about Cheryl getting her lab results, another type of lottery, I guess. I'm so glad you stuck in there instead of running away. And that you finally got the housing even in the customary care cohort is awesome.

You know, at each of these Summits, I pick up some new-to-me technical terminology that I incorporate into my vocabulary. The study participants gave me the best one this year: “Stayed stopped”. “Stay stopped.” I love that term. I understand exactly what it means. And I want you to know that you all aren’t the only ones in this room who might need to “stay stopped.”

One of the things I zeroed in on at this Summit that was identified at our first one is that the AIDS world is still way too focused on individual interventions as the key prevention strategy. And if we remain wholly dependent on those, our efforts will fail. Yes, condoms and clean needles are important. But we need systemic interventions and we need structural interventions. As the subject panel made clear, housing is a structural intervention that works.

So, the work continues. In the breakouts and report back this morning, we discussed next steps in policy-based research and next steps in research-based advocacy. It’s now up to each one of us to get on with implementation. Each summit to date has generated new questions that have provoked new research. The policy papers that have come out and the tool kits are just the baby steps we’ve taken to use this information. Yesterday’s panel on use of research to develop advocacy campaigns should inspire similar campaigns all over the country.

We also need to share this wealth of resources around the globe. (It has been so good to have input at this Summit from Canada, India, and South Africa.) I hope that some of you will be inspired to participate in the International Summit on Homelessness and AIDS at the international AIDS conference this summer. If you do, you will actually be able to meet Esther Boucicault and Sandra Banda in person.

Out of H&H and CHHP alone, we have enough fodder to gather again next year, and will probably be hearing important findings coming out of those studies for several years to come. But I hope many of you are inspired to go out and develop research or policy efforts using the research already available.

I’m thrilled that TJ’s exploration of brothel housing came out of his attendance at our last research summit. We also need to make sure that next year’s summit is not only in a larger room, but that the room is filled with government and private funders of research and of policy makers.

But I want you to know that these summits are not an easy thing to pull off. In addition to your registration fees, we had to raise nearly \$180,000 to pull this thing off. David Holtgrave has already offered Johns Hopkins’ support for next year; and I am incredibly grateful for that. But the committees that put this together are a tiny handful of people, most of whom do this out of passion and on top of their already over-filled day jobs.

So I hope you will consider becoming involved in the summit planning group. And if you can’t do that, at the very least, join NAHC, pay your dues, and consider becoming a sponsor of next year’s summit, or, if you are already a sponsor, please consider increasing your sponsorship.

I still believe that housing is a human right. But I also know that I can chant that until I am blue in the face, and it won’t supply one more unit or house one more homeless person. As Shirlene so aptly said it on Wednesday, “Advocacy without research is just a temper tantrum.”

We need to prove what we know is right, and then demand it and make it so. Then perhaps we can give every homeless person with HIV not just enough to keep him or her from dying, but enough so that people can really live their lives whole. I know that Esther, Sandra and Cheryl would truly welcome that.