RHTAC webinar, November 30, 2011
Clinical Care for Refugees with HIV Infection

Dr. Paul Geltman: Good afternoon, everybody. This is Dr. Paul Geltman. I'm the medical director of the Refugee and Immigrant Health program and the Refugee Health Technical Assistance Center at the Massachusetts Department of Public Health. And I want to welcome you to our webinar today. You should be seeing the welcome slide in front of you. We are just going to wait a few minutes to give additional people time to log in as it always takes a little time. People run a little late. So just hold tight and we will get started maybe in about five minutes. Thanks.

Hello again, everyone. This is Paul Geltman. I'll be the moderator for the webinar today. We are just going to wait again maybe one more minute, maybe two to get started. People are still logging as we can see the number of attendee stats fully continuing to climb. So just be patient with us another minute or so and then we'll get started.

Okay. I think we're going to get started. So let me just quickly introduce myself once again. I'm Dr. Paul Geltman, the medical director at the Refugee and Immigrant Health program and the Refugee Health Technical Assistance Center at the Massachusetts Department of Public Health.

Before I forget I would like to acknowledge our funding for the technical assistance center and it's for this webinar comes from the U.S. Office of Refugee Resettlement, and I'd just like to acknowledge and thank their support for our work. We're just going to start with some basic housekeeping instructions so let me get the slide going here.

Okay. You should be seeing a slide that says housekeeping at the top. And this shows you the user interface for the Go To Webinar system and the attendee interface. And there are two parts. The viewer is on the left which allows you to see everything the presenter will share on their screen. And right now you're seeing my slides. And the control panel will be to the right side of your screen and that's the little box window.

Within the control panel is how you can participate in the webinar today. So we're going to just to take a moment to look at that. Now just quickly we had a little technical problem in one of our webinars over the summer, or actually it was earlier this fall, where the presenter clicked on that x in the control panel. You do not want to click on that x ever because that will close the webinar window and you will log out and be gone. So then you'd have to sign back in and everything and get started again.

So don't touch that. If you need to open or close the panel you use the orange button here on the left, which is boxed in in red. You'll right now the arrow is pointing to the right. If you click on that it will close it off to the right side as just like a little like traffic light there that will appear in the top right corner of your screen.

And you click on it again and it will open it back up for you. Now you can also use the view settings to set it to keep the control panel open. You may not want to do that though. Now during the webinar because of the large number of participants we will not be having people speak. You can submit questions to our presenter today using the control panel which will have a box as shown here for questions. And you type your question, and then hit the send button and it will come to the webinar staff and we will present them to our presenter for a response as we can.

This item we are not going to use so please don't worry, or panic or wonder why you're being ignored if you click that button. Know from the start that we are not using the hand raising function for comments or questions. Again if you have a question, type it in the question box. Hit the send button.

Now we are hoping that we're going to have plenty of time at the end for about anywhere from fifteen to twenty-five minutes of question-and-answer, so during the course of the webinar send us as many questions as you want and we will get to them as we can at the end of the presentation. However, all of the questions that are submitted will be answered by our presenter, Dr. Crosby, in writing. If she doesn't get to them during the webinar they will be posted on our website after the fact.

Now I think this is the last piece on this slide, but please we have everybody muted, but if you have a mute option on your phone on your end that's probably good as a backup too. All right, lastly we will ask you to do an evaluation of the webinar. Normally this appears as a popup box as you're signing out. However, for this time we're going to email it to you after the webinar concludes and it's very brief, but very important to us in terms of getting feedback for the quality of our work and the quality of the presentation. So please just take the minute or two required to do the evaluation questions that we will email to you.

Okay. So as an overview for today we are going to hear a presentation by Dr. Sondra Crosby, whom I'll introduce in just a moment. The presentation is on caring for refugees, asylees and immigrants with HIV infection.

The presentation will be about forty-five to sixty minutes and then the remainder of the time hopefully up to about twenty-five minutes will be question-and-answer. The slides, a recording of the live webinar which includes the slide presentation as well as question-and-answers and resources will be posted on the website of the Technical Assistance Center, which is written out here, http://refugeehealthta.org. The webinar recording and the slides will go up very quickly, within hours to a day or two at the most, but certainly before the end of the week we will have the webinar recording and slides posted.

And we will try to have all the question-and-answers and resources posted within one to two weeks, more likely to be two weeks though. We have to be fair to Dr. Crosby to give her a chance to think about them and respond. Lastly if you have questions about our work or want to send a note you can email us at refugeehealthta@jsi.com.

So again before I introduce Sondra Crosby we are going to do a poll of our participants just to get a sense of who you are. I think we have a few of these scattered throughout the presentation and this is we're going to do two right now.

So first is we want to know who you are. And as a quirk of the system I actually see the results so I'm going to move just here and just take a moment to click on one of those categories. Are you a healthcare provider or a clinician of some sort, including nurses? Are you a refugee health program staff person? Do you work at a resettlement agency as a case manager or other staff? Are you public health professional or some other category that you would like us to know about?

So I'm going to give a count to five and then we're going to close the poll. Five, four, three, two, one. Okay.

So our results show that nine percent of your healthcare professionals, thirty-five percent are refugee health program staff, twenty-one percent work at a refugee resettlement agency, and twenty-five percent of you are public health professionals and the remainder checked other.

Okay, now I think we have a follow-up poll that we're going to do as well and this is for us to get a little sense of how many of you actually work with refugees who are HIV positive.

So again ten seconds to give us a response on this and then we'll show you—I'll announce the results. Okay, five, four, three, two, one. Okay so about a third of you, thirty-two percent provide direct clinical care to refugees with HIV and so obviously the remainder of you, two thirds or so do not.

So let me introduce our speaker for today and it's really a privilege for me to introduce Dr. Sondra Crosby, whom I've known for many years. Dr. Crosby received her medical degree at the University of Washington School of Medicine and she completed her residency in internal medicine at Boston City Hospital, which is now Boston Medical Center. She is a practicing primary care internist and was formerly co-director of the Boston Center for Refugee Health and Human Rights at Boston Medical Center and she is an associate professor of medicine at the Boston University School of Medicine.

Her clinical practice at BMC focuses on the care of asylum seekers, asylees and refugees. She has written over 200 legal affidavits documenting medical and psychological sequelae of torture and she's published multiple papers in peer review journals in the field of caring of survivors of torture and recently was awarded the Leonard Tow Humanism in medicine award by the Arnold P. Gold Foundation. So with that again I would like to thank her for being willing to do this presentation for us and I'm going to turn over the presentation to Dr. Crosby now.

Dr. Sondra Crosby: Thank you, Paul, and welcome everybody for being here this afternoon. It is a great pleasure to be part of this webinar series. I am going to be talking about caring for refugees, asylees and immigrants with HIV infection, which is something I've done now for about the last ten years.

So my objectives for this afternoon are to review the principles of screening for HIV infection and refugees and immigrants coming to the U.S. to increase awareness of potential issues that impact the care of HIV positive immigrants, including refugees, asylum seekers, and to learn strategies for successful engagement in medical care and treatment of HIV positive refugees, asylum seekers and immigrants. Fortunately the overall growth of the global AIDS epidemic seems to have stabilized according to the 2010 U.N. AIDS report.

The majority of the 33.3 million people living with HIV AIDS around the world is still centered in Sub-Saharan Africa and in South and Southeast Asia as you can see here. And these are areas of the world where many of the incoming refugees to the United States originate from.

Immigrants and refugees in Massachusetts are disproportionately affected by HIV AIDS. In Massachusetts from 1999 to 2009 the proportion of people born outside the U.S. among those diagnosed with HIV infection has increased from eighteen percent and has remained in the last few years between twenty-eight and thirty-two percent. And this is despite the fact that the number of foreign born people in the Massachusetts is twelve percent.

Furthermore the proportion of females diagnosed with HIV AIDS and born outside the U.S. has increased from twenty-seven to forty-six percent in this same time frame. In addition from 2007 to 2009 thirty-seven percent of foreign born immigrants diagnosed with HIV had already progressed to AIDS at the time of diagnosis, compared to thirty percent of U.S. born. So this means people not only are disproportionately represented, they are also being diagnosed at a later stage of the disease.

This graph represents in Massachusetts that fifty-four percent of blacks diagnosed with HIV from 2007 to 2009 were born outside the U.S. And that is compared to thirty-four percent of Latinos and eight percent of whites.

Minnesota has reported similar trends in their HIV diagnosis of foreign born people. And according to their 2010 surveillance report among new HIV infections diagnosed in 2010 eighteen percent were among foreign born persons while they only make up five percent of the total Minnesota population.

These trends that we're seeing have important implications for HIV prevention and designing treatment programs. Those of you working in the refugee field probably already know this, but prior to 2010 refugees were screened for HIV infection as part of the overseas medical examination. And those with it that who tested positive for HIV infection were deemed inadmissible without a special waiver.

Beginning January 4, 2010 testing for HIV was no longer defined as a communicable disease of public health significance and testing for HIV was no longer required as part of the immigration medical screening process. And HIV no longer requires a waiver for entering into the U.S. or for adjustment of status for people applying for licensed permanent residency.

So many refugees are coming to the U.S. from countries with a high prevalence rate of HIV, as we saw in the previous map. So it is important that HIV testing is offered to refugees after they arrive in the United States.

In 2006 the Centers for Disease Control, the CDC, published recommendations for HIV testing in the U.S. that favored a knocked out strategy. Now what is this? This is routine voluntary HIV screening that is not based on risk and should be performed for all persons ages thirteen to sixty-four in the healthcare setting unless the patient declines, unless they opt out, and repeat HIV screening should be done annually for those with non-risk factors. They also recommended that a special consent form should not be required.

So how is this implemented for a refugee population? I advocate for universal testing in refugees and immigrants who come from countries with high HIV prevalence. And we already saw that the African and Asian continents have very high prevalence rates of HIV. So this is even going beyond the age recommendation of the CDC.

And what are the benefits of universal HIV testing? It eliminates the need to ask about risk behaviors and reduces stigma associated with targeted programs that require assessment of risk behaviors. HIV should be normalized or HIV testing should be normalized as a part of standard screening in the medical setting.

And this is I think especially important in refugee populations. And targeting high risk groups such as men who have sex with men or IV drug users means that you're asking refugees questions that might be offensive because of religious or cultural taboos. And for instance we've actually had patients become angry when we've used public testing forums where the screeners are mandated to ask questions about risk behaviors.

So care must be taken to approach these questions with sensitivity in a manner that's culturally appropriate to the population. And for many populations I don't use the public Rapid HIV screening programs. I just screen for HIV as part of my routine testing in the clinic.

The case for universal screening, so I'm just going to talk to you about a patient in my practice and this is why I screen regardless of the age of somebody coming into my practice. This is Ms. M and I have a whole cohort of patients like her that I've collected over the last ten years.

She's a sixty-eight year woman from Sub-Saharan Africa who has been followed by a primary care provider for a little over five years. She was sponsored by her daughter and when applying for a green card she was found to be HIV positive with her initial CD4 count of thirty-eight. A normal CD4 count for a non-clinician is between 800 and 1,200, and a viral load of 200,000, which is very high. So this means she is diagnosed at an advanced state of disease.

She is this adorable frail grandmotherly-like woman who just does not fit the kind of the U.S. stereotype of somebody with HIV infection. And indeed upon asking her and reviewing her chart she had never been counseled about or offered HIV testing, although her country of origin has a very high prevalence of HIV.

The situation with Ms. M is really unfortunate because we've missed the window of opportunity for treating and this could possibly negatively affect her response to treatment and prognosis. And what do I mean by that?

This is some natural history of HIV data from the multicenter AIDS cohort study that essentially shows the risk of progression of HIV is correlated to CD4 count and by reload. So you can see here on the chart the higher the viral load and the lower the CD4 count the higher risk of progression to AIDS.

The rationale for diagnosing Ms. M early and treating her is based on clinical data. And there's no substantial body of clinical data showing a survival benefit of earlier therapy.

And this study looked at the rates of death or disease progression over three years among patients initiating antiretroviral treatment, or AIDS treatment, based on what the initial CD4 count was at the time of treatment initiation. And as you can see here from this bar graph the lower the T cell count at the initiation of therapy the higher the risk of death.

And you can see her, Ms. M is down in an area where there is a risk ratio of death of 19.3. And in addition to CD4 count the progression to AIDS morbidity and mortality is also more likely in patients with viral loads great than 100,000, which she also fits into that category.

So we've missed an opportunity with her. One more slide looking at a cohort study, patients treated with antiretroviral therapy which demonstrated that those with the baseline CD4 count of less than 200 had a more rapid three-year disease progression than those who had a baseline count of 200 to 350.

So just in summary here there's a substantial body of data demonstrating the benefit of early diagnosis in treatment of HIV. Now antiretroviral viral therapy is still beneficial in patients with low CD4 counts less than 200 like Ms. M, but there's not as much of a benefit as if she had been diagnosed and treated earlier in her disease.

So now that I have made the case for universal testing of refugee populations immigrating from high-risk countries I—and I think that the domestic refugee health assessment visit is a very appropriate setting for many if not most patients to be tested. I just want to raise a couple of points that have come up in my practice over the years about pretest counseling that should be considered.

In some cases in some refugees testing for HIV may be more appropriate in the primary care setting after a trusting relationship with a provider has been established. Clinicians and others who work with refugees should be aware of the potential fear of [stigmatization], which can be real. And I'll give some examples later on.

Testing may just trigger painful memories and recollections of those who have died or it may trigger flashbacks if flashbacks if HIV risk in that patient includes trauma including sexual assault. So I think the bottom line here is I think the refugee help assessment visit is the best place to do HIV testing and counseling. However, this is where your clinical judgment is critical

and supersedes guidelines and protocols. And there are some patients who where testing may need to be delayed.

I'm just going to give an example of a case where this didn't work out so well for me. All of these cases that I'm giving are people in my medical practice. So this is a twenty-nine year old woman from an African country in conflict who I counseled and tested for HIV. And when she was told about her positive test she became hysterical, started having flashbacks, literally moaning and wailing on the floor, saying that she wanted to die.

We spent hours in post test counseling and support with an urgent site consult, social workers, medical workers and just help make a safety plan, got her treatment, helped her make a plan to stay in Boston. She didn't want to go home. And the whole situation created a lot of unnecessary chaos for everybody, and mostly because I hadn't prepared well enough for post test counseling for her.

And I think mental help and psycho-social support needs to be part of any HIV testing strategy. It's important to have a conversation about knowledge, health belief and experience prior HIV experience for people that she knew and this all probably could have been at least ameliorated if not avoided if I had taken proper precautions to start with.

I should have elicited her history and anticipated the need for better support. She also revealed in post-test counseling that she had been raped and that was her explanation for how she acquired HIV. So this brought also brought back some frightening recollections and some PTSD symptoms. So the take home point that I have from this case is to prepare and it illustrates how important an integrated approach to care and counseling and testing of this vulnerable population is.

Stigma and education around HIV testing should also be addressed at the community level in addition to the individual counseling and testing level. Engaging communities and religious leaders can reduce stigma and increase knowledge about HIV AIDS in immigrant communities. And when a respected minister advocates for HIV testing it has much greater impact than really than often anything I can do.

In this example we collaborated with a Ugandan minister who advocated HIV testing within his community and at his congregation. And we performed HIV counseling and testing as well as provided other health education at a community celebration. And this approach was very successful.

So in summary HIV testing should be considered at the initial refugee health assessment visit, but clinical judgment should always be exercised. There are a few situations, however, where testing needs to be prioritized and that is in pregnant women, in breast-feeding women. If you suspect serial conversion illness, and that is acute HIV when you initially become infected with HIV and develop a febrile, an acute illness immediately after or within weeks to a few months after, and any signs of opportunistic infection or illness that might be related to HIV.

So here this is going to be first poll question. This is a thirty-nine year old man from a Sub-Saharan Africa country who presents for his initial refugee health assessment.

Except for a remote history of malaria he reports no previous medical care. He has no significant complaints at this visit. Physical exam revealed the following lesions that you can see here on his foot.

And for the clinicians they were hyper pigmented, not painful or itchy. And upon question he thought they may have been there for a few months, but wasn't really sure.

So this question is really directed at the clinicians. And these are the choices for diagnosis, Bartonella, bacillary angiomatosis, ectopic dermatitis, Kaposi sarcoma, malignant melanoma or a fungal infection.

Paul Geltman: So hi this is Paul Geltman again. We're going to give you five seconds to respond and I'm going to present to you results since under the presenter doesn't get them on her computer. So five, four, three, two, one.

Okay. So seven percent said bacillary angiomatosis, ten percent said ectopic dermatitis, fifty-two percent went with the big one, Kaposi sarcoma, fourteen percent said malignant melanoma and seventeen percent said a fungal infection.

Sondra Crosby: Well you guys nailed it and you are a better diagnostician than I am because I did not make that diagnosis. And this is sort of a trick question because a biopsy was actually required to make the diagnosis and the answer is Kaposi sarcoma, which is a malignancy associated with HIV.

After the biopsy the patient subsequently tested positively for HIV, got into treatment and did fine. And just one the points I want to make here is one that Doctor Stauffer made last month at his webinar and that is that some refugees coming into the country have never had medical care or even a physical exam before. So that initial physical exam at the refugee health assessment visit is very important.

I want to say a word about HIV in refugee women, who are the majority of infected of adults in Sub-Saharan Africa, North America and the Middle East and in fact the majority of infected adults in my clinical practice. Some of the reasons are increased physiologic susceptibility. Women are often victims of human rights violations, for instance subordinate positions in the family.

They've had unequal access to medical care or education, unequal voice in decisions in the relationship and possibly domestic violence. In some women some of these issues will present barriers to engaging in care after arriving in host countries and must be considered.

Also rape has been used as a weapon of war. You can see this quote here. We are not killing you. We are giving you something worse. You will die a slow death, taunted the mercenaries who raped and mutilated the Tutsi women, some as young as twelve after killing their men folk.

Some of the refugee women with HIV have experienced sexual trauma and this is also something that needs to be dealt with in the clinical situation with a multidisciplinary team. In addition refugee situations are conducive to forced high risk sexual behavior to gain needs such as food.

So I'm going to move into clinical care or HIV infected refugees and it's probably no surprise to you that there is a paucity of evidence-based data to inform the best practice of care of HIV infected refugees. A lot of work needs to be done and it just isn't out there yet.

In one study, Beckworth et al in Rhode Island published a retrospective case control study which compared the demographic and clinical data from HIV infected refugees with matched HIV infected non-refugees. They compared variables such as HIV acquisition risk, disease co-morbidities, HIV stage upon establishment of care, anti-retroviral utilization, enrollment in clinical studies and adherence with appointments.

So I'm just going to show you a few of the results here. And their findings were that the refugee group was more likely to report HIV risk as heterosexual transmission, eighty-one

percent versus sixty percent of the non-refugees. They were less likely to use alcohol or engage in intravenous drug use. And as you can see here they were more likely to have latent TB infection, twenty-seven percent versus zero percent in the non-refugees.

They were more likely to have active hepatitis B infection, nineteen percent versus zero percent. As you can also see here the CD4 count and viral load were similar among the two groups.

A very important finding of this study as well was that although refugees and non-refugees had similar stages of disease refugees were less likely to start antiretrovirals, fifty-six percent versus seventy-nine percent. They were also less likely to have participated in clinical trials.

And yes this is really significant and given the data I presented earlier about the importance of starting antiretroviral therapy this finding definitely warrants further investigation into the cultural and social factors that predict successful engagement in HIV care, including acceptable and preferred antiretroviral regimens. The authors of this paper postulated that communication challenges around the use of antiretrovirals may have been contributory to fewer refugees initiating HIV treatment during the course of this study. Again much more work needs to be done on examining the factors.

In another retrospective chart review of a cohort of thirty-four HIV infected refugees in Boston seventy-seven percent had experienced torture, including twenty-three experiencing rape. And it's important to note that thirty-five percent were exposed to HIV re-situations as a consequence of torture. And this was mostly in the context of sexual assault.

In this cohort there were high rates of mental health diagnoses. Fifty-six percent were diagnoses with major depression and thirty-two percent were diagnosed with posttraumatic stress disorder. Again I think this highlights the importance of an integrated team approach to this patient population.

This is another study that was performed in Boston where HIV positive refugees, Latinos and U.S. born were assessed across domains of psychological, psychosocial and physical health functioning through in-depth qualitative interviews. They assessed the following domains, posttraumatic stress disorder, number of traumatic events, depression, mental health related quality of life, physical health related quality of life, stigma around HIV, social support from the family and social support from the community.

And as you can see here the refugees scored higher in number of traumatic events. They scored higher in HIV related stigma and they felt they had less social and community support around their HIV diagnosis.

Interestingly the refugee group reported greater physical health related quality of life than the other groups. The PTSD prevalence rates were approximately the same among all groups and this was an intercity hospital population so that is not surprising.

So in conclusion refugees reported significant isolation from their community and perceived considerable HIV related stigma. The authors postulated that the combination of elevated psychosocial and psychological distress may be associated with greater barriers to healthcare and difficulty integrating into American society for HIV infected refugees.

They also concluded that clinical programs to great refugees living with HIV that integrate physical healthcare and assistance with psychological and psychosocial functioning may be warranted. So this really underscores the common theme of an integrated multipronged approach to treating this vulnerable population.

So I want to remind everybody to submit questions that we can answer at the end. You can submit them right online.

So what do we know about barriers to HIV testing and treatment? Foley et al published a qualitative study describing the experience of African immigrants and HIV AIDS in Philadelphia. Barriers to HIV testing and treatment included fear of the legal system, linguistic barriers, fear of the American health system, misunderstanding modes of HIV transmission and a prominent theme was lack of disclosure to partners and social risk associated with disclosure.

I want to emphasize that in my experience over the last ten years that these risks of disclosure are real and can present dangers to the women. Through the interviews these investigators found that privacy and confidentiality were more important than overall health status.

African women in this study had limited power to negotiate condom use or testing of partners. Through interviews these investigators found—they also interviewed service providers and found that service providers voiced frustration and insufficient resources to care for this population.

Next case is also a patient of mine, a thirty-seven year old woman who had been tortured and is seeking political asylum. She is extremely paranoid, which worsened after 9/11. She does not want to fill out any personal information on hospital registration forms. She does not pick up her HIV medications in the pharmacy because she has heard a rumor in her community that immigration is monitoring pharmacy records. And she ultimately ends up developing resistance to her HIV regimen.

I think this case illustrates lack of trust and the belief that health professionals report to immigration service that can be held by individuals in some immigrant communities. And this may have actually happened to people in their own countries where health professionals did report to the government. It illustrates the need for trust building and education about confidentiality, and our legal system and confidentiality of hospital records.

Attention to basic needs may be the immigrant or the refugee's first priority. For example they may be most concerned with safety, food and clothing appropriate to the weather and not with their HIV care. Other needs include lack of housing, anxiety over separation from children and family safety back home, potential legal needs, lack of employment or lack of access to English language classes.

And I'm going to give another example of a woman from my practice, so a woman also from Sub-Saharan Africa who presents for HIV care. She is a single mother with six young children. She is illiterate, has never gone to school and after being in the country for a few months she is already in trouble with the police and DSS. She has done some commercial sex work on the side to help make ends meet.

This woman was in survival mode fueled by high levels of distress and this is how she survived the civil war and provided food for her children. And she resorted to those means.

In response to all the chaos going on with her we did a home visit, a case manager and myself. There was a pile of mail in the corner, all of it unopened. She was illiterate and couldn't read it. And so she just kept piling it up. So she was not paying her bills. She wasn't responding to correspondence about school issues with the children, including some legal problems, et cetera.

So we needed to deal with all of her urgent issues that required intensive case management support, increased support for the kids, getting her into school. And once all of

these issues were addressed adequately she was ready to accept antiretroviral treatment for her HIV, but just was not able to do it until we dealt with these other priorities first.

This is one more of my patients. She is a thirty year old woman who is failing her antiretroviral therapy, has become resistant to her regimen. It is finally discovered after months that she is sending a portion of her medications to Uganda for a family member who is unable to get therapy for HIV AIDS.

And for her the expectation to provide for her family overseas was a barrier to successful antiretroviral treatment. And the amazing social workers and case managers worked with her and just it was important to acknowledge the global problem of the availability of AIDS treatment and explore her own therapy within this context, working through her guilt over family members left behind and unable to get treatment.

I want to say a word about interpreters. We are all familiar with the use of interpreters and there's data to demonstrate that low English proficiency patients are more likely to report problems with care and are more at risk to experience medical errors. This is especially important given the complexity of HIV care.

The literature also suggests that optimal communication, the highest patient satisfaction, best outcomes and fewest errors occurred when LEP patients have access to trained professional interpreters. And that is opposed to family members, friends, other people who might be in the clinic who speak the language. The one thing I consider in my clinic frequently and especially in the HIV clinic is in person versus phone interpreters.

For sensitive topics an anonymous phone interpreter may be preferred by the patient. I know in many cases the in person interpreter may be a member of the local community and a discussion of sensitive topics such as HIV status, torture, trauma, GYN issues may be shameful or embarrassing. So I will often offer the anonymous phone interpreter.

This is one more patient in my clinic, a thirty-nine year old female with depressive symptoms, severe depressive symptoms, PTSD, who refuses a mental health referral or medications for her depression because she is "not crazy." In addition she does not want to use the hospital Arabic interpreter because he is from her community and goes to her mosque.

So just to recognize that there may be stigma of mental health treatment in some cultures and important, the importance of exploring the cultural context of mental health as in this case being equated with crazy what has worked for us is actually incorporating mental health services into the primary care or the HIV clinic, which may decrease stigma and normalize mental health as part of routine services. I actually have, will have the mental health clinician come into the exam room and see the patient right then and there. I also focus on treating symptoms, for instance sleep and not a mental disorder.

Other challenges that I have already mentioned, touched on this a bit in this trust of the medical, mistrust of the medical system there is data to show that African Americans, Latinos and Asians are more likely than whites to believe that they will be treated unfairly in the healthcare system. We've had people had bad experiences, afraid of getting bills, viewing the doctor or hospital as part of the government, not understanding the confidential nature of the relationship. And one thing that has come up in the HIV clinic is the immigrant has fear or discrimination or of arrest and deportation because of their HIV status if they are undocumented, so again other barriers to overcome.

It also goes without saying that our healthcare system is complicated. In many cultures people will only go to the doctor when sick and not by appointment. And refugees and

immigrants may not be familiar with a preventative healthcare model that we endorse in this country and medical procedures.

In particular HIV care can be very complicated, requiring frequent medical visits and monitoring blood draws that may be uncomfortable or unfamiliar. Transportation and childcare may also present barriers when people require frequent appointments. And we try to attempt to consolidate appointments, think about childcare and perhaps provide transportation vouchers.

Even the idea of appointments may be new. This is a clinic in Guatemala where people just show up, and sit and wait their turn. So the new immigrants and refugees will often need orientation, also orientation about the roles of providers and staff and perhaps depending on the refugee's background education about understanding the biomedical model.

This is another young man that I see in my clinic, twenty-two years old from Sub-Saharan Africa, feels that having blood drawn as is required for HIV, and by the way for people with HIV and especially starting therapy they may need frequent blood draws. He says it makes him feel weak. He also says that giving up blood is fundamentally wrong and he refuses blood draws on occasion.

He is labeled noncompliant by the staff. So his belief needed to be respected and explored. And it was a new concept for him that blood was constantly being regenerated in his body. He didn't understand that.

And what we did while providing education was to work with him, minimize blood draws as much as we can. We carefully planned around his preferences, i.e. he played soccer. We didn't draw blood before soccer games. So eventually now he has issues with getting his blood drawn, but it did take a period of education.

Here is going to be the second poll. This is another patient of mine. This is a female in her mid-thirties with HIV. She's from Sub-Saharan Africa. She came to the U.S. as a refugee ten years ago from a war-torn African country, is now a U.S. citizen and actually a graduate student.

She is on HAART with a T cell or CD4 count of greater than 400 and an undetectable viral load, meaning she's very well controlled. She was brought to the emergency room after a witnessed generalized seizure.

This is her MRI, which I'm just going to point out here this lesion in the right what is the frontal cortex. And it is a cystic lesion with a thin ring enhancement and the white stuff around it is edema or swelling of the brain. So the diagnosis is—

Paul Geltman: Okay. So your choices are AIDS related CNS. That's cranium central nervous system lymphoma, toxoplasmosis infection. That's a type of parasite, CNS tuberculosis, neurocytoma, a type of brain tumor or neurocysticercosis, another type of parasite infection. And I'm going to count down from five now, five, four, three, two, one. Time's up.

Okay. And here are the results that we have. Thirty-eight percent of you selected age-related CNS lymphoma. Thirty-three percent selected toxoplasmosis. Thirteen percent said CNS tuberculosis, neuro tuberculosis. Four percent said a neurocytoma and eleven percent said neurocysticercsosis.

Sondra Crosby: Okay. This is also kind of a difficult one. All of these choices are on a differential diagnosis for central nervous system lesions in HIV infected patients. However most of them occur with CD4 counts that are lower than hers, lower than usually 200.

So this is actually a classic finding for neurocysticercosis, which is what she has. This is the most common [helmet] infection of the CNS and is endemic in the developing world, including many areas with high rates of HIV.

Neurocysticercosis is reported to have a higher case fatality rate when there is HIV co-infection and it actually may flare with the initiation of antiretroviral therapy, something called the IRIS, which is immune reconstitution inflammatory syndrome. And that is when there's an inflammatory response after initiation of antiretroviral therapy that can lead to worsening of subclinical infections.

Now this is very interesting. So she, the patient reported that she had been experiencing these spells since she was approximately ten years old. So that's also a tip off to the diagnosis.

And I didn't tell you that so I'm sorry. I withheld that important information, but although I had cared for her for almost ten years at the time of her diagnosis of seizures I had failed to list the history of seizures and she had never sought medical care for the seizures. She explained that she thought the seizures were spells of spirit possession by her ancestors. Other family members had these seizures and she did not think this was a medical phenomenon.

She was subsequently treated with Albendazole, Dexamethasone and an antiepileptic drug and has remained seizure free. So this was a very humbling experience for me and illustrates cultural differences and explanatory models of disease.

So beliefs as to the cause of HIV and the patient's explanatory model is important and needs to be explored in order to understand the patient's knowledge base. Preconceived notions about HIV are not limited to immigrants. I want to make that clear, but can be complicated by the discordance in culture between health professional and the patients.

Some themes that we have encountered, denial of HIV status, just lack of knowledge or erroneous knowledge, community perception without symptoms there can't be illness nor risk of transmission, fear and shame of stigmatization, which we've mentioned, fatalistic beliefs and modes of transmission. These are some quotes from my clinic:

"HIV is a death sentence." " HIV does not exist and may represent an effort by the West to control other parts of the world." " HIV is punishment from God." "Homosexuality will result in imprisonment or death." And this one, last one is important. "HIV infected persons cannot marry or have children." I have had more than one patient who had been in my care for months just break down in tears when they suddenly realized that it's okay for them to date or have a relationship, get married and have children because they had just assumed that it would not be legal for them to do so.

Tompkins et al surveyed an immigrant and refugee Sudanese population in Nebraska about HIV knowledge attitudes as well as risk behavior and these results demonstrated that a significant number of the population were poorly educated about HIV and exhibited attitudes and beliefs that may increase risk for HIV and create barriers to care. Fifty-five percent thought HIV was transmitted by mosquitoes. Forty percent thought HIV was transmitted by a cough or a sneeze. Fifty-five percent thought they were protected if they had sex with persons who looked healthy, very interesting.

Forty percent thought they could get HIV from a public bathroom. Thirty-six percent thought HIV was punishment and deserved. A large proportion of this population engaged in high risk behavior.

In some refugees coming from some cultures we have encountered resistance to condom use at least initially upon arrival. People who may whose cultures or religions may oppose pregnancy prevention and impregnation of a woman is a sign of virility, condom use would

indicate HIV positivity and so a woman would not want to or decline to advocate for condom use with their partners or husbands and lack of empowerment of women. One example it stands out to me in a focus group of refugee men, some of who opposed pregnancy prevention, one man said birth control would be like interfering with God's garden, so a lot of education.

This is a retrospective chart review of twenty-eight female refugees with established care between 2000 and 2006. There were twenty pregnancies among fourteen women, so this is a fifty percent pregnancy rate among the refugee women. Median time of first pregnancy from resettlement was sixteen months.

During this same time period HIV infected non-refugee women were the rate of pregnancies in HIV non-infected refugee women were also looked at and was about thirty percent, so a significant difference, so a very high rate of pregnancies in this cohort of refugee women and I think this really highlights the need for timely initiation of medical care, including comprehensive family planning and pre-conceptual counseling. Again we see many pregnancies in our own institution, and an area that needs further attention is disclosure, planning for pregnancy and pre-conceptual counseling.

And going to quickly talk about this patient in my practice, a twenty-one year old male refugee whose family arranged a marriage for him in Sudan after arranging the payment of a hundred cattle, he's going to return for the wedding, but is concerned about condom use, which condoms are not used in his village. And he's worried what people will think.

With this particular young man we have done a lot of counseling over time and in the cultural context of protecting his wife, his new wife, we have provided a lot of education on protecting women from harm. And I think highlighting education in men is very, very important.

Developing trust with refugees, immigrant [health] populations is essential for the development of a therapeutic alliance, and where you really talk frankly about HIV. And this can be difficult. And this is just a theme that I think probably all of us, all of you understand who work in the refugee communities.

Exploring patients' beliefs, knowledge about HIV treatment and working from their baseline is something we've demonstrated. Be aware of severe shame and stigmatization around HIV and be prepared that talking about HIV may trigger bad memories in some patients.

I think this is my last example, a twenty year old male refugee becomes very angry at me during a clinic visit after I happily tell him he doesn't need HIV medications because his viral load is so low and his T cell count is very high. He yells at me, accuses me of holding, withholding medications from him because he's African.

I later learned from the interpreter that the patient thinks medications cure HIV and I'm withholding him. And I did not do an adequate job of assessing this patient's baseline knowledge of an experience with HIV prior to talking to him about medications.

Some traditions and customs that shape one's culture have an impact on health and wellbeing. And I try to incorporate traditional practices that are important to my patients when possible.

In addition especially with HIV care talking about fasting practices such as in Ramadan and other times during the year is also important. This is an example of a man from Southeast Asia with HIV and we treated his HIV with a combination of cupping and with antiretroviral treatment, so just an example of the cup.

Another point that I found to be very important is confidentiality of treatment sites. And many patients prefer treatment sites that don't specifically specialize in HIV. I literally had the

experience of finding a patient hiding behind a pillar in the waiting room because she saw somebody else from her country in the waiting room and did not want to be recognized.

Quickly other testing considerations in HIV positive refugee populations, people coming from Africa tend to have different viral clades, different subtypes. And we don't know a lot about what the implications on this are for testing or for treatment and for resistance testing. And this is an area of research, also consideration of HIV-2, which is endemic and common in Western Africa and should be thought of.

There are recommended screening tests for refugees with HIV that are in addition to some of the tests that Dr. Stauffer reviewed in last month's webinar. And I am just going to go through these quickly. I am providing references at the end where you can go back and look at these in more detail.

And in addition to testing recommended in refugees and domestic screening for people with HIV infection we do an initial CD4 count of viral load, initial resistance testing, chemistry panel, lipid testing, syphilis testing, just keeping in mind there are higher rates of false positive syphilis tests and so they need confirmation. Hepatitis B serology is similar. We do toxoplasmosis serology when people present with HIV because there is a high rate of reactivation of toxoplasmosis infections in AIDS patients.

Tuberculosis testing is the same except the positive cutoff for the [men] two test is five millimeters and not ten millimeters. And it should be repeated annually if negative. We do T6 PD testing and pap smear testing because of the high risk for cervical dysplasia. Again I provided references for more information about testing.

Just a word about vaccinations in HIV infected refugees in general there a couple of caveats when people have HIV infections. Generally in activated viruses are acceptable and we try to be careful about why virus vaccines. And they should be avoided in advanced disease.

Vaccinations however are important because HIV is a risk factor for diseases that can be prevented by immunization. Also important to realize that vaccine efficacy may not be as good in people with advanced disease. So as you can see here tetanus series is the same. Polio in activated polio can be given. Pneumococcal vaccine is very important. HIV patients are at significant risk for aggressive pneumococcal disease, although it should be given at a T cell count greater than 200 and can be repeated if it's initially given when the T cell count is less than 200. It should also be given a second time after five years.

Influenza vaccine is important. Hepatitis B is also important, although there might—there is usually a less of a response to the hepatitis vaccine and post vaccinations serologies to be tested.

It is important to note that the usual measles, mumps, rubella and varicella vaccines are contraindicated if the CD4 count is less than 200. However they can be considered in people with more intact immune systems.

Antiretroviral therapy has come a long way from the days when I first started treating HIV where we gave 16, 18 pills a day. We now have very simplified regimens, even once daily therapy. Use of med boxes makes antiretroviral therapy much easier. Having a pharmacist as part of the therapeutic team is very important to help manage pills, manage side effects, issues with the pharmacy and ongoing adherence.

One word about contraction with latent, about contraction with latent tuberculosis and hepatitis B, Dr. Stauffer covered these last month, HIV and tuberculosis are—can be a big problem and contraction requires aggressive treatment, identification and treatment. So he talked

about the importance of testing. I just want to say that HIV increases the risk of tuberculosis and tuberculosis is a major cause of morbidity and mortality in HIV so testing is important.

Latent TB infection in HIV infected persons carries a very high risk of reactivation so it's very important to test and treat. Treatment is effective and this can be—testing can be either done with the MEN 2 test or the interferon gamma release assay.

People with HIV infection coming endemic countries are also coming from countries where hepatitis B is endemic and contraction needs to be identified and also managed. Co-infection with HIV increases risk—it increases progression and in some of the sequela of hepatitis B infection including faster progression just to cirrhosis or end stage liver disease, so just knowledge of this in co-management with experts is important.

It takes really a team and ongoing assessment and monitoring for readiness to engage people and to keep people into therapy, as we've already discussed. We don't know a lot about outcomes of HIV treatment in immigrants compared to non-immigrants in the U.S. We do know there is higher death rates in minorities than non-minorities and longer delays to treatment in minorities.

I just want to end again with emphasizing the team approach, which is probably the most important underlying theme today. I could not care for my patients without a competent, intact and multidisciplinary team.

A lot more research needs to be done in the area of improved methods of care for HIV infected refugees, need for comprehensive and coordinated care among all of caregivers and agencies and community-based education. I have provided a resource to look for a comprehensive AIDS information, which also includes many other references about very specific antiretroviral treatment and prophylaxis. So I think we're now open to questions.

Paul Geltman: Yes. Thank you, Sondra, for the wonderful presentation. And if people have questions send them in now. We've got about fifteen minutes left and we've had some coming in already. And I'm going to just start by merging a couple that came in early and quickly answering because I'm going to guess Sondra won't have an answer to these.

They were about whether what was the percent of refugees who applied for a visa overseas that were denied because of HIV and could or could not get a waiver, and whether people doing HIV testing of refugees overseas notified the refugees of their status and had training on how to do that. And I'm going to guess the, right, Sondra is saying no she doesn't know those numbers.

I actually can probably get that data from either the director of our program, Jennifer Cochran, or from the CDC. However I just want to remind everybody that HIV testing was removed from the overseas assessment of refugees and that this has not been an issue now for a year or so.

And there was a slide earlier that referred to inadmissibility and that was the old standard when HIV was considered a class A condition for which you had to get a waiver approval to enter the United States. And that's no longer the case. It's no longer even tested for.

So the first question that I'm going to pose to Dr. Crosby is I'm going to paraphrase it. What are some best practice models for research and clinics that are successfully integrating primary care and behavioral health for HIV positive refugees?

Sondra Crosby: There has not been—I'm sorry. There has not been a lot of published data, in fact none that I know of specifically for best practice models for integrating primary care and

mental health for HIV infected refugees. However I think the model that we use and other centers use is to have mental health, primary care, case management, social work, pharmacy all in the same physical space. So this is really like a medical home that patients can come and receive comprehensive care.

Paul Geltman: Okay, thanks.

Sondra Crosby: But there actually is a recent paper that I can post to Paul that's not specifically about refugees. It's about this model for HIV care in general. And I think it works very, very well for the refugee population.

Paul Geltman: Okay. So there's a question that I think came in response to my opening comments here of whether this means now that refugees may actually have HIV when entering the U.S. and be unaware of this. And that gets to the slide Sondra had earlier where she said very few there was a statistic about very few refugees who were already here having HIV. And that's because they were screened out.

Now that is no longer the case. Refugees are not, I repeat, not tested for HIV before entering the U.S. And in fact, yes, we are discovering as you would expect that there are refugees who are HIV positive and that's why the recommendation is now for universal testing of refugees to be offered as part of their domestic health screening, or if they don't have one in primary care just like is the recommendation for the general population in the U.S. So again it is no longer part of overseas health screening of refugees in any capacity.

Now I'm going to give a quick question to Sondra. The speaker mentioned that five millimeters is considered positive for skin testing for tuberculosis in HIV positive patients instead of ten millimeters. In our clinic we use the IGRA. That's the interferon gamma release assay of blood tests that's available now. And the positive number is 0.34 or higher. Should that number be lower for co-infected patients or is the positive threshold for all patients? And I'm—that's a tough question.

Sondra Crosby: That's a really tough question. And I did not see any differential in cutoff in my reviews of this issue, but I'm actually happy to readdress that and we can post that. And, Paul, do you know of any—?

Paul Geltman: I certainly don't know and there are some contraindicated populations for the IGRA type tests which are relatively new and still with some controversy around their use, but we can ask our medical director or our state TV program to give us a response to that one and we'll post it with the responses, the written responses within a couple weeks. So look for that on our website.

So let's see. There's a question about what to do if your patient doesn't have health insurance. And unfortunately that's really a state by state issue until at least the affordable care act kicks in. So I'm going to skip over that question because what we do here in Massachusetts is by no means representative for the rest of the country or the other forty-nine states and other territories.

So another question is do you feel that the current cultural competency education models in medical schools prepare you or prepares other physicians for working with HIV positive

refugee populations? How good was your cultural training in medical or residency I'll say to build your capacity to deal with refugees with HIV?

Sondra Crosby: Yeah. I would say my experience is what not—at my experience was the training was not adequate either in medical school or residency. And that is something that we're striving to improve here through rotations, through refugee health, didactic courses and really working with the medical school to incorporate this as a more formal part of the curriculum.

Paul Geltman: And I will say also that there are a lot of schools now, I'm going to guess the majority if not most medical schools and residency programs have some kind of courses or curricula in cultural competency that it has really become mainstream whereas when I was a resident and Sondra was a resident almost two decades ago these didn't exist. I didn't get any kind of cultural competency training and I think I went to a pretty good medical school.

I didn't get any really significant cultural competency training until I was in my fellowship and after almost kind of educating myself a bit. And that's not the case now I will say.

So there's one more question since we have a few more minutes. I'll pose this one to Dr. Crosby and we do have about five more minutes. So if anybody has additional questions type them out really quickly and we'll try to get to everything live now online.

So the last question that I have queued up is I'm going to expand it a little bit. And the question was about the slide that you showed on cupping. And so the questioner I think basically wanted to know what do you think is the therapeutic benefit that refugees expect or perceive from the cupping procedure, presumably for HIV or whatever ails them?

Sondra Crosby: In this particular case let me just step back and say that I care for a broad spectrum of refugee and immigrant patients who come with a very broad spectrum of traditional medical treatments that they utilize. And it has become very clear to me over the years that most patients, or many patients, do not share these traditional treatments with their typical Western doctors, either because they don't think their doctors will take them seriously, they're embarrassed. They don't think their doctors will respect them. So I make it a point to be proactive and be very respectful and ask every patient about all traditional or nontraditional, Western nontraditional.

For them this is actually traditional with all treatments that they use, and try to incorporate them. And this gentleman and other patients that I have had get a great deal of relief from pain, relief of mental health symptoms from their traditional treatments.

And what I try to do is create a treatment plan with a patient that utilizes a combination of Western treatment. And if they have something they want to use that they have used that is important to them I will try to incorporate that.

Now again the other important thing as a clinician is to make sure they are not using anything that is harmful or that may have drug interactions with any other treatment they are getting. I have patients who do cupping. I have a lot of patients who take herbal medicines, flax seed.

I do a lot of acupuncture in my refugee patients and some of my patients actually go to traditional healers in addition to coming to me for things. So for this man this has he attributes

his successful HIV treatment in part to the cupping that it's weeding out the bad blood that's causing the HIV.

Paul Geltman: Okay. I'm just going to make a couple comments and we have one more question that came in. And then I have a question which if there is still time we'll get to.

The two comments are just for the non-clinicians when Sondra was talking about testing for tuberculosis she talked about the TST or MAN-2 test. TST stands for tuberculosis skin test or tuberculin skin test and that the MAN-2 is just a proper name for it.

Many of you may know it as the PPD test, which is purified protein derivative. Those are all just synonyms for tuberculosis skin testing. And also as a pediatrician I want to just emphasis when Dr. Crosby was talking about the contraindication to live viral vaccines in people with low CD4 counts and HIV that that does not apply to their household members.

And it's very important to if you have an HIV positive parent to make sure that they're getting their children fully immunized, not only to protect the children, but to protect them as well. I'm going to just look. Another question came in and I'm going to try to decide whether would I want to ask or that should go next, so one second.

Okay. This is a question that we're not going to be able to answer so we'll address it through the written responses if we can about the audience's access to intensive medical management and other health navigator programs. We don't know that really now. We would have to look more detailed at I guess institutional affiliations and make a guess if we can. So I'm going to pose a question that will be our final response from Dr. Crosby that I want to go back to when she was starting to talk about of the social stigma, and emotional stress and even reactivation of mental health problems like PTSD around the issue of testing and the diagnosis of HIV.

And putting this in the context of that in and of itself the emotional distress or mental illness presenting its somatization, how do you juggle what might be somatization from emotional stress versus a physical manifestation of HIV? And then also can that level of emotional distress exacerbate the physical condition of HIV patients?

Sondra Crosby: Good questions and I am not sure I have the answer. Often times especially initially it's hard to know what is somatization.

Paul Geltman: Sorry, I just cut Dr. Crosby off because I realize some people may not know what I am talking about. Somatization is when you have a physical manifestation of emotional distress. Roughly that is what it is so I am feeling stressed out about something and I get a headache or a stomachache. So go ahead, Sondra.

Sondra Crosby: There are high rates of somatization in my refugee population, especially when they first come and are having acculturation difficulties and all of these other stresses that I talked about, it is very, very common to have physical manifestations of stress. It's also very common to have physical manifestations of mental health problems. Depression may manifest as total body pain or stomach pain, or severe headaches and it is often hard to work those out. So there is not an easy answer to that. And your second question was?

Paul Geltman: Well can the emotional distress itself cause a physical deterioration because of the compromised health status I guess of having HIV?

Sondra Crosby: Certainly the stress can cause physical problems. I don't think there is any data to show that it worsens the course or advances the course of HIV, not to my knowledge.

Paul Geltman: Okay. So we have to end here. It is 2:30 now and I think there are one or two a couple questions we didn't get to live which we will have written responses to. So again I want to thank Dr. Sondra Crosby from Boston University in Boston Medical Center for spending the time with us this afternoon or this morning for some of you I guess, and just remind you that we will have the question-and-answer response and posted hopefully within a couple weeks and within a day or two at the most.

We will have the webinar recording as well as the slide set available on our website which is refugeehealthta.org And lastly just a reminder that we will have our next webinar I believe in January 25th in this same time slot 1 to 2:30 and it will be Dr. Michael Hollifield talking about screening for mental illness in refugees and specifically introducing the newly developed fifteen item questionnaire which he has worked so hard on validating and developing and now we are helping with dissemination of it.

So you can register for that and we'll hopefully we will have you back with us in January. All of our previous webinars by the way are available on our website if any of you missed them and want to listen or view the slides. And a word for the clinicians I say this every time, but we are still working on having CME credit for these webinars. You are not allowed to get retroactive credit for having listened today, but you will be able to view the webinar online, and take a short quiz and get credit, but we still have not this approved yet.

So all I can say is coming soon if you would like CME credit keep looking for them. Hopefully by January we will be able to offer it for the webinar, but again I hesitate to make any promises since it has been taking so long. And my last reminder to everybody before we close is that you will get an email very quickly, which will have the evaluation questions or link for the evaluation for today's webinar, which we are learning each time we go where the potential technical glitches are, and I think this may be our first time after four or five that I don't think we have had any. So I would like to congratulate Allison who is our technical support person here. Anyway thank you all and have a good afternoon.