HIV at 50+
Kaiser Family Foundation
July 24, 2012

[1] The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

[START RECORDING]

LAURIE GARRETT: Good afternoon everybody. It's wonderful to see a packed house for this very important discussion. My name is Laurie Garrett; I'm Senior Fellow for Global Health at the Counsel on Foreign Relations. If you missed the sign outside and you think you might be in the wrong session, we're talking about HIV in over 50 year old populations.

This is a huge issue that is trending heavily at the moment. Indeed, the meetings – poster sessions – are just rife with details on what's turning up now in the older HIV populations. If they're not mentioned, these things, by our panelists as we go along, I'm going to bring them up.

A few key points to consider: huge plummets in Vitamin D levels, huge increases in kidney stones and kidney and renal failure, increases in bone fractures and osteoporosis, increases in a wide range of carcinomas – not just those commonly referred to as AIDS associated – dramatic increases in cardiovascular disease - hypertension, stroke, lipodystrophy and elevated LDL cholesterol - increased depression, increased suicide, increased hyperparathyroidism, decreased neurocognitive functions, increased frailty, overall increase in inflammatory responses and a dramatic increase in the shortening of telomeres on chromosomes, meaning direct cellular aging.

If you're not so depressed now that you need to leave [laughter], what's dramatic about all of this is that we're so early in the research that it's very hard to separate which of these problems are associated with side affects with medications – not just ARVs but other medications that HIV patients may be taking – which are direct biological effects of the virus itself over time and which are due to misalignment of the immune system that has been caused by the slow disease process.

It's urgent that we figure the answers out because by 2015, in North America and Western Europe, half of the HIV population will be over 50, and believe me it won't be long before many resource scarce countries – particularly up in the Lake Victoria area where the epidemic is quite old in Eastern Africa and eventually even in Southern Africa where the epidemic is newer – will begin to experience the same dramatic shift in the age distribution.

We have a very important conversation and I'm asking Dr. Amy Justice to come to the podium to start us out by laying out the ground work so that we better understand what's going on. Amy is a perfect person to explain this for us. She's been working on HIV for 20 years, and for many recent years she's been working with the Veterans Aging Cohort Study. These are all military veterans in the United States monitored over a

long period of time; one of the few cohorts that allows us to begin to tease out what is causing which problems. Amy.

DR. AMY JUSTICE: Thank you. [Applause]. Wherever anti-retroviral therapy is available, the good news is people are aging with HIV. Life expectancy at the start of ART for a 35 year old male with a CD4 count at initiation of 100 cells, in the United States was estimated at being between 30 and 37 additional years based on older data. Based on more recent data in Uganda, the estimate was 35 to 39 years, suggesting that increased life expectancy based on anti-retroviral therapy is not that dependent on where you're getting the medication.

More people are living and aging with HIV now than ever, and their numbers increase each year. I think that's a very important fact to keep in mind. Not only are people aging, but the total number of people that we're caring for with HIV is increasing every year – in resource limited settings as well as in resource rich settings. In the United States it's 38,000 additional individuals every year. In sub Saharan Africa it's been estimated at nearly ten-fold that.

Current prevalence in one particular part of Africa, here in South Africa, has recently been measured and then weighted to be representative of South Africa more generally, and broken down both by gender and by age. As you can see, for 50 to 59 year olds, nearly 12-percent of women in that age group are HIV positive in South Africa. The numbers remain

quite significant, even up to 70+ years of age with a rate above 3 percent – both for men and for women.

This map illustrates the point that was made just a few minutes ago about what we might expect to see with respect to aging in sub Saharan Africa. The top three maps represent the prevalence of HIV among populations who are 15 years of age to 49 years of age, both for the current situation – 2011 – and then all the way up to 2040.

The bottom three maps illustrate that for 50 years of age and over. What I want you to look at is the darker colors that represent greater than 15-percent prevalence. Currently that lies with the younger age group, but by 2040 it will be over 50 years of age.

Another point to make is that while I'm going to be giving you a lot of statistics, aging occurs in individuals. Individuals who vary as much by other characteristics as they vary by their age. That story is very nicely told by the greying of AIDS. It's a website that tries to bring together pictures, stories, videos of people who are aging with HIV. Currently they have mostly people from the United States, but they are quite eager to collect the stories of people from around the world and I would recommend you stop by and see them.

Incidents will rise with prevalence. Sex doesn’t end at 50. I would consider that also good news for all us

[laughter]. Sexual activity in the United States: 84-percent of men and 62-percent of women over 50 reported sex in the last year. In South Africa, 63-percent of men and 30-percent of women over 50 reported it in the last month.

Risk of transmission is greater given exposure among those who are older. Among men in the U.S. who are 50 years of age and over, they were six times less likely to use condoms. In Uganda, men who are 50 years and over were more likely to have STDs than younger individuals and 40-percent remain sexually active after an HIV diagnosis. Women have thinner vaginal walls which likely increases their risk of transmission given exposure.

We need to think very carefully about how to prevent transmission among older individuals. We need to consider carefully to what extent microbicides, STD treatments, prep, should be adapted to this population and how we will educate this population about their use. HIV does not and never has occurred in a vacuum.

Before aging was an issue, care was complicated by multi-drug regiments that were susceptible to non-adherence, resistance and toxicity; to many co-infections including Hepatitis C, Tuberculosis and multi-drug resistant Tuberculosis, and to major socio-economic issues including stigma, addiction, incarceration, homelessness and under-nutrition.

We've been dealing with these complexities from the very beginning. Now we add to that mix chronic non-infectious disease. Here's data, again, from South Africa summarizing multi-morbidity by age. As you can see, whether you're talking about hypertension, angina, diabetes or disability in general, the rates increase with increasing age.

Incident disease in resource rich settings is also increasing and in resource poor settings. Here's data from the Swiss Cohort from 2008 to 2010. They observed 1,189 events among 8,444 patients. Of note, only 16-percent of the events observed were HIV events.

The rest, 84-percent, were non-HIV, and here's the relevant incidents of those conditions: 17-percent were bacterial pneumonia events, 13-percent were fractures, 11-percent were MI or a PTCA – which was presumably to avoid an MI; of note, there were more PTCAs than MIs – 10-percent were cancers, seven percent were peripheral vascular disease events, five percent were osteoporosis, five percent were liver disease events like cirrhosis, three percent were kidney disease and two percent were pancreatitis.

One thing I would like to point out is the five percent osteoporosis versus the 13-percent fracture rate, which I think underscores the complexity that we're dealing with. Osteoporosis is determined based on bone mineral density, but

more than half the people who have a fracture from thin bone do not have osteoporosis by bone mineral density measurements.

In fact, if you looked at the number of fractures that the Swiss Cohort observed, more of them were associated with trauma than were not. Now, all else equal, if you have thin bone, whether its trauma or not associated, it's more likely to fracture. That's why we really need to think holistically about how we're going help people improve their quality of life as they age.

We also need to think about the limits of the silos of care that we have created. We need to think about coordination and communication. As long a we're providing HIV care in one setting, Tuberculosis care in another setting and chronic disease care in third setting – if we're providing it at all – we have a real problem with communication and coordination. Especially if we actually start to use medications in all three of those settings. It's going to become increasingly critical that everyone communicate with each other, and that we coordinate and prioritize care.

Like cancer, inflammation, frailty and disability are multi-hit phoneme. Disability, frailty and functional status are three geriatric concepts that are increasingly applicable to those aging with HIV. Each is a consequence of the total disease burden or physiologic injury suffered by the patient rather than any particular diagnosis.

Again, we have to think about the fact that people have more than one thing going on. Of note, these concepts also relate to cognitive dysfunction, especially delirium and dementia. The classic situation in geriatrics is an older individual comes into the hospital, another medication is added or they have a new infection, and they become delirious and can't think straight. We need to consider those impacts on cognition as well.

Here is a conceptual model that underscores these points. When people come into care for HIV, they frequently have at least one other condition whether it be viral Hepatitis, Tuberculosis or substance use issues. These conditions and their treatments then interact in an interacting pathophysiologic process including immune dysfunction and senescence, microbial translocation – also known as leaky gut – chronic inflammation, HIV and non-HIV treatment toxicities, oxidative stress and associated comorbid conditions. None of these act in isolation. They all act in the same physiologic meule, and we need to understand them together and intervene on them together.

Together they cause incremental depletion of organ system reserve – also called frailty – which can lead in turn to cognitive and functional decline, organ system failure, repeated hospitalizations and nursing home placements and eventually death. Our goal is to detect these changes early

enough that we can effectively intervene and prolong quality of life as well as quantity of life as people age with HIV.

Just to underscore this point about he multiple hit phenomenon, here's some data concerning inflammatory markers. In this case I'm showing IL-6, but the results would be similar if you were looking at d-dime or soluble CD-14. This data was recently published in the *Clinical Infectious Disease Journal*. Here we compare, in the blue, those who do not have HIV to the green, folks with a CD-4 count greater than 500 who are HIV positive; the orange, those who are positive with a count that's more intermediate – 200 to 499, and in the red, those with a CD-4 count less than 200.

The first model is unadjusted for comorbid conditions and behaviors that can cause inflammation. Here the referent group actually has a slightly higher risk which is statistically significant than those with very high CD-4 count and HIV. What is important is that as we progressively then adjust, first for smoking and alcohol and then for comorbid conditions – that's the third model – we begin to see a much stronger affect of HIV. The point being that all of these conditions contribute to inflammation. HIV is not acting in a vacuum.

Further, it's not so much that age is accelerated as it is accentuated, and let me explain what I mean by that. There was a lovely paper in the *Annals of Internal Medicine* by

Shiels, et al, that asked the question, given that the underlying population of people aging with HIV is on average younger than the general population, are we misconstruing the ages at which these events are occurring? If we adjust appropriately for the difference in the underlying distribution of age in the population, are the differences less pronounced?

They began by looking at people who had AIDS conditions and developed cancer and then compared those to people from the SEER data sets who had cancer. They found that after looking at 26 different cancer diagnoses, that for 18 cancers there was absolutely no difference in age once you adjusted for the underlying difference in age distribution in the population. The remaining I show you on this table and you can see that the age adjusted differences are really fairly small. So what were apparent differences of 23 years, 12 years, 17 years, dropped to five and four years. [Break in audio].

Now that is not to say the risk is not increased; it is. But that's accentuated not accelerated. So people are at increased risk for these conditions at conventional ages; at least based on actual clinical events. Interestingly, if you look at bio-markers instead, if you look at bio-markers of inflammation, if you look at bio-markers of cardiovascular disease, you might reach a different conclusion. In those cases, frequently, it looks as though individuals are

substantially older. The disjoin between those two observations is part of what we need to begin to understand.

Poly-pharmacy may be accelerated in resource rich settings. Poly-pharmacy, which is typically defined as being on five or more chronic drugs at a time, is associated with diminished marginal benefit from additional medications due to both non-adherence – people just get confused because they're on so many pills – and adverse drug events.

Now this is not just drug-drug interactions. This is any adverse drug event, and they include confusion, falls, renal failure, etc. The risk of adverse drug events in the general population increases approximately 10-percent with each additional medication beyond five. So if you're on 10 medications, you reach nearly 100-percent risk of having an adverse drug event of at least one.

I include this table not to make you learn all of these numbers, but just to make you look at the kinds of adverse drug events that we see in the general population and what drugs they are associated with. The first one listed here is falls while receiving benzodiazepines. How many of us have patients in our clinics who are on benzodiazepines?

Symptomatic orthostasis after receiving anti-hypertensives. Falls while receiving opiates. Hypernatremia while receiving diuretics, etc. These are all medications that we are commonly using among our patients as well.

Here is comparative data from the VA looking at those with and without HIV, again aged matched, and you can see that at every age decile, whether you're talking about 40 to 50, 50 to 60, 65 or over 65, there is an increased number of medications – chronic medications – among the HIV positives. So here is an example of premature poly-pharmacy. Numbers of daily pills are also similarly advanced at every age group, and we clearly get into the range that we're beginning to worry about poly-pharmacy.

Health risk assessment can provide an essential roadmap. One such risk assessment is the Veterans Aging Cohort Study Risk Index, and here's a summary of its thresholds and weights. The index uses routinely collected clinical data including age, HIV specific bio-markers, CD-4 cell count and viral load, and bio-markers of general organ system injury: hemoglobin, Fib-4, estimated GFR and Hepatitis C.

Fib-4 and estimated GFR simply require a creatine the estimated GFR, AST, ALT and platelets for the Fib-4 calculation. These are all routinely collected and recommended according to guidelines in resource rich settings. The restricted index is simply a comparator index restricted to CD-4, viral load and age.

One point that I would like to make before I move on from this slide is for you to look at the weights. Look, for instance, at the weight for CD-4 count less than 50. The

weight is 46 for the restricted index and 29 for the more complete index. Suggesting that when you look at other bio-markers, the weight you give to CD-4 count is reduced. Similarly, the weight for hemoglobin is really quite strong. For hemoglobin less than 10 you get 38 points.

I'm not saying this is necessarily the truth, I am saying only that we need to consider how these other factors play in. We do have some preliminary data to suggest that the vast index is fairly useful. It predicts all cause mortality not only in the VA, but among Europeans and among North Americans. According to ART-CC at NA-ACCORD cross-cohort collaboration validations, including all cause, HIV specific and non-HIV as well as cardiovascular disease and risk of mortality can be estimated over a five year window.

It predicts morbidity including hospitalization, MICU admission and fragility fractures. The fragility fracture data is reported here at this meeting. It's correlated with functional performance and symptom burden, and it's responsive to changes in risk after ARV initiation, ARV intensification and ARV interruption.

Further, as aging patients near the end of life, priorities of care need to change. Aging inevitably means that we need to be thinking about end of life, but in a very different way than we used to think about it. Patients want to know when they are within five years of death because they want

to prepare, they want to make the most of the remaining life that they have, and they want to make appropriate medical and health related decisions in light of that information.

I'd like you to conduct a thought experiment with me. What if, when a patient walks in to see their provider, they could work with them together to identify and prioritize all the major risks that patient was exposed to?

They could then quantify the harm and benefit from interventions in meaningful terms including risk of hospitalization, disability and mortality. The patient and the provider choice could be informed by this evidence and by the patient's personal preferences for these outcomes. We could then use the same risk assessment to motivate change and map progress, and finally, to identify end of life to signal the appropriate changes in priorities that that dictates.

Some important caveats. HIV and aging caveat number one: we have a sense of what's going on for those who are 50 to 64 years of age, but really not a very clear sense of what's happening beyond 65 years of age. That's simply because the cohort studies that are trying to report this data don't have that many people in that age group yet.

The reason this is important is because the association with age is not linear. When an individual gets beyond 65 their risk steps up fairly dramatically. This is, again, data from the Swiss cohort, and if you look at the stroke data you

can see that when you compare 50 to 64 year olds versus 50 year olds, the risk is relatively modest. But when you look at the light blue, the risk goes way up after 65, and this is true for many other conditions as well. We will learn a great deal more as time goes on.

Finally, like all politics, aging with HIV is local. When we think about what are the similarities and differences between the first and second waves of aging with HIV, we have to think about access to non-HIV treatment, which, while being variable in North America - depending on the coverage of different health plans – it's very little in sub Saharan Africa.

Experience with aging in general is extensive in the United States and North America, more generally in Europe; we have very little experience with that in sub Saharan Africa. The population in question in most of the developed world are special populations, not "the general population", where it is more likely the general population in many of these other countries. Prior exposure to mono and dual therapy is quite different.

Again, in resource rich settings there is a great deal of that; there's very little in other settings. Common co-infections differ. Common chronic diseases are actually remarkably similar, and as we get more and more data, we're convinced that they're more similar than we might have guessed.

Major additional challenges include homelessness, incarceration and under nutrition.

The priorities for second wave: improve surveillance data on those 50 to 64 as well as over 65. Consider how to tailor prevention for older individuals. Compare methods of coordinating multi-morbidity care. Develop and validate cost effective risk assessment tools. Consider harms and benefits both of adding treatment and of subtracting treatment. Study HIV pathophysiology in the context of multi-morbidity. Thank you. [Applause].

LAURIE GARRETT: As Amy joins us, let me explain what we're now going to do. We're going to have a conversation on stage until about 3:20, 3:30, something like that, and then open it up for your questions. Since we're going to have an ongoing conversation, you might jot down your questions so that you can remember them when we open up the microphones.

We have an absolutely fantastic, ideal group of people with us here on stage to really tease out the significance of the very powerful information that Amy just gave us. It reminds me that my step-mother had an embroidered pillow that she'd had commissioned done that was quite beautiful, that was on one of her living room sofas.

It was embroidered with this: Aging, it ain't for sissies. [Laughter]. That was when she was 80, and we're

talking here about 51 being old, and for those of us that are well ahead of that, that's a little unnerving.

I want to start by asking Ron Rosenes for a particular set of insights. Ron's the perfect person to start with. For one thing he comes from a country that has universal health coverage, so that gives us a chance to have a conversation independent of the question, could you get access to care? He's Canadian, and for well over 20 years he's been an AIDS activist in Canada.

He is with the AIDS Committee of Toronto; their act without the up, and Chair of AIDS Walk, on the steering committee of the Canadian AIDS Russia Project, and involved in a long list of activities both inside the Canadian government and outside. So Ron, my question to is simply this.

I want you to try to lay out for us in really pragmatic and clear terms – anecdotal – what is it like to be simultaneously dealing with having carried this virus in your body for ages and now you're getting an onslaught of one aging associated – or HIV associated, we don't know – syndrome after another? What is it like? What's your daily life like? What do you hear from your friends and colleagues?

RON ROSENES: Well, first of all thank you for the invitation to be here today. I was pleased that you noted that this is a trending item, and for people who know me, if it's trendy I want to be there [laughter]. I found the room which

was great. I flew to Washington all by myself and found the room which is good.

Amy, you talked about aging being local, I also thought of the feminist expression that the personal is political, because if I talk about myself – which I don't really love to do because I think I've had certain advantages – I want to be able then to extrapolate to the broader points.

I have, in fact, been living with the virus for over 30 years, and when I talk about this in community I sometimes say to folks in community that I am a survivor in the sense that I've been through the early days of the plague, and I've witnessed all the massive death and dying and loss that came in the early days of the epidemic.

I'm also a witness; I'm a witness to all of the amazing advances in science and hope to witness even more. I am also now, in addition to being a survivor and a witness, I'm a pioneer as a member of this cohort. Just a few days ago I had milestone – I call it a millstone, other people call it a milestone – it was a 65th birthday which was pretty exciting. [Applause]. Thank you. Thank you.

And guess what? I've had, among my advantages I've had private long-term disability insurance and it has basically enabled me to do long-term, high level volunteer work. It has literally afforded me a kind of salary to do work over the years in community. It came to an end last week, and I'm going

back to work. So anybody who wants my CV, we can talk later. [Laughter]. I'm going back to work.

As someone who has been advantaged in terms of the Canadian health care system to a degree – although I don't want people to think that our system also hands out medications, it doesn't work quite as universally as everyone would like to imagine – I have had, by virtue of living in a big city, access to pretty good resources.

Because I am fairly proactive about my health and began at an early stage, at a time before we even had medications, to look into all the various things I could do to clean up some bad habits - including a long history of smoking - and some recreational drug use – which I have to confess to like Sir Elton John yesterday – but having gotten through all of that, I'm grateful to the health care system.

I'm grateful to the resources that are offered to me in a big city, but I'm very conscious of what needs to be done in terms of understanding this issue for people who don't necessarily live in a major urban center.

I come at this problem looking at is as someone who's had some advantages. As someone who has already been well screened for cognitive function, with a baseline battery of tests, with follow up years later. I'd really like to get into that; talk about that a little bit more.

I have been screened for osteoporosis, which runs in my family, and which I have. So I can talk about treatment for bone disease. I can talk about cardiovascular, which I manage in a bunch of different ways.

And I would like to also basically offer the initial observation that, I think, that if there is any kind of good news—because there won't be much after I say this—but if there's any kind of good news, it comes from what you were saying, Amy, about the accentuation, as opposed to the acceleration. And I think, if I understand that correctly, then the corollary is that the fewer comorbidities that you have, the less likely you are to have these accentuated problems.

So, we need to look at HIV in the context of aging with HIV, as one of a number of additive factors. And I'd also like, to say that, in my experience of it now, when I look at the graphs and look at the description, I feel there's something missing. And I think it is the impact of depression. I see a lot of it in the communities around me.

I think that aging, in and of itself, is a tremendous source of clinical depression, and I don't see it reflected always on these charts, as being a major contributing factor.

So, there's just a few initial thoughts. I'll stop there and we can pick more stuff up later.

LAURIE GARRETT: Well, thank you. And I think one of the things that comes through is, you're seeing—you're interacting with the healthcare system quite a bit, which is affordable to you because you're Canadian. But, Nils Daulaire, it's not quite as affordable for those of us South of the border.

Nils is—Dr. Daulaire is the Head of the Office of Global Health Affairs, in our Department of Health Services. He's been in this game of global health and HIV for decades. I think, for many of us who recall his days in USAID in the Clinton administration, or when he was running the Global Health Council. After that, we recall him as a real advocate for women's health, and one of the few men whose voice resonated on behalf of women's health, including women with HIV.

One of the weirdest things, and very disturbing for me about Nils, is that he speaks seven languages. So, I wanted to ask you an awkward question, for the United States, for a U.S. Representative, because we have about 50 million Americans without health insurance, and another many millions with inadequate, or bankrupting health insurance, if they are looking for the kind of concentrated care that was just described to us, they're not going to be able to afford it.

In some ways, that puts us in a particularly good position to understand resource-scarce countries. Because,

though we have the availability of a perfect line of services and HIV-positive person deal with this complex cascade of AIDS, many in our populations cannot afford to access it.

What do you think are some of the most important take-home messages from that?

NILS DAULAIRE: Well, let me start with good news, bad news. The good news is, in fact, that if you—I believe the terminology is, elderly is above 65, older is above 50—I'm closer to elderly than I am to older. But the good news is that the elderly, above 65, in fact, do have better access to services and to the resources to pay for them, thanks to Medicare, a program that's been around for 50 years.

Then people who are a bit younger, certainly than the older group, or even the younger than older group, the reality is that this is an area in which there has not been much attention paid and, largely because those who have been on the front lines of advocacy, of engagement, haven't really been part of the cohort.

I'm just curious—it's a good audience here, in terms of turn-out, but could you just raise your hand if you are above 50? Hands in the air, please. Pretty good turn-out. Would you raise your hand if you're under 30? Alright. Not very many.

Imagine an AIDS conference in which the vast majority of people at the AIDS conference had to be HIV positive to be

interested and to attend. We need to have much more engagement of young physicians and nurses and researchers who can help to move this field forward. In fact, my suggestion to the organizers of this session was, we might have more of them if, instead of the title we gave it, we called it Geezers Gone Wild [laughter].

That said, I think it's probably true that the best thing you can say—the most positive thing you can say to a young person who has just discovered that they're HIV-positive, is, someday you will be old. That is, in fact, an aspirational aspect.

So, our challenge here, then, is to look at the ways in which we can assure that happens and then provide the care. I think there are a lot of young people, and I appreciate, Amy, your comment early on, who don't realize that when you get to be over 50 and over 65, that people still have sex. They don't realize that for the most part it is not safe sex. They certainly don't imagine that, in many instances and in particular communities, it's with multiple partners. And they probably do recognize the degree to which older people are very, very unaware of HIV, it's prevention and its consequences.

So that sort of lays out an agenda for where we need to go, and I'll come back later and talk about some of the issues in prevention and the research that needs to be carried out.

LAURIE GARRETT: Thank you. Dr. Hiroki Nakatani comes to us from Geneva today, where he is the Assistant Director General of the World Health Organization in Charge of HIV. So, he's the perfect person.

He's also perfect for two other very important reasons. He comes from a country with universal health coverage that happens to have the oldest population on earth, and, before taking his current position, had real expertise in the human resources crisis in health around the world. It's hard to imagine anything as human-resources intensive over time, as managing geriatric complexities, to begin with, and now with an over-layer of HIV on top of it.

We look around the HIV world today, and one of the most striking problems we have is the lack of sufficient labor force skilled in all aspects of what we call health, from lab technicians to MDs, RNs, community health workers, you name it. Now you're going to add this whole other, complicated layer over top of it. Are we prepared, as a global community, to take on this whole additional layer and dynamic to the HIV problem?

DR. HIROKI NAKATANI: Thank you very much. That is very challenging question, as usual, Laurie. I would like to start at—you said aging is local issue, but if you look at globally, you would be quite surprised that WHO had status support of NCD, in 2010. It's very surprising.

I thought—or I imagined that NCD knows disease, or knows some problem. But if you look globally, I think more than 60-percent of death is coming from NCD. And if you look at developing countries, the figure is slightly, but not significantly less. So that tells how important NCD is.

But, I think you were right. I think we need to face this dual challenge of NCD and HIV, and my other portfolio is NTD, so three challenges we have. But how can we address these challenges? I think we have a variety of challenges, including financial challenges. Let's be honest, HIV—maybe Peter you will add later—NCD international budget or resources now flattened. But I think, locally, developing countries and putting on their own resources.

But still, I think the gap is large. And in addition, how are we going to address NCD? That is really challenging. But I think, still we need to go. One way to think about it, is to integrate services. So we cannot have separate systems, of vertical tuberculosis program, vertical HIV program, vertical cardiovascular disease, vertical disease program—we can integrate. And perhaps this is the kind of work that we need to have serious change. I see one of the areas which HIV communities must be very proud of—that is, I think, the U.S. government for support, that is, task shifting activities.

So, I think, what doctors have been doing can be shifted nurses. Nurses' work can be shifted to community

health workers, provided that there is good quality assurance on the kinds of exist. So, I think committee levels, community workers, can provide a lot of services. Otherwise, we cannot afford it, and we feel that when we expand our services, we oftentimes think about drug prices. Drug price is important, but I think [interposing] is very, very interesting.

LAURIE GARRETT: But what you're saying to us is, if we hope and dream that the global budget for dealing with non-communicable diseases, the NCD Challenge, and building up health systems that can deal with it, is going to increase to the levels that people hope and dream it will, then handling the aging HIV population will be doable.

DR. HIROKI NAKATANI: But I think we still need more resources, but we cannot expect that the sky is unlimited blue. We need to see about reality. Within this reality, still we can do much more.

LAURIE GARRETT: Peter Giese, who is the Chief of the Data for Action Division of USAIDS Program in Geneva, another person who has come from Switzerland for us today. This morning, we heard a very striking presentation in the plenary from your colleague Bernhard Schwartlander, from USAIDS, laying out a whole set of scenarios for funding the HIV epidemic response, going forward.

But not included in any of those cost estimates, was the additional burden of cost dealing with people who have

geriatric disease, whether it comes prematurely, or not, as Amy was noting, but perhaps with greater severity and more complexity. If you really look out at the big picture, what are we talking about here? How can we possibly imagine that we can raise enough money and have enough personnel and enough clinical support to be able to deal with people over 50 with HIV disease?

PAUL DE LAY: Thank you. For that question. Let me say that, in the plenary that you were referring to, where Bernhard spoke, that some of those—that, first of all, he indicated as also Nakatani mentioned, that there is already an increase in the financing domestically by the most affected countries, and that he also laid out various options for raising more finance, both in affected countries to various types of tax or other means. But also, international sources of finance that could be brought to the response to AIDS.

So, many of the numbers that he quoted are way beyond the 7 billion that he mentioned, which is our current gap. A lot depends, of course, of the will to go forth and implement some of those items and options, both in affected countries and in donor countries.

Then, one other point to make, building on what Dr. Nakatani mentioned, is that somehow there is, indeed, a need for integration between care for HIV through ART, and programs that address non-communicable diseases. It is because HIV,

itself, has become a chronic condition. Then HIV, itself, or its treatment, leads to some non-communicable conditions, itself. And then, just through the aging of populations worldwide, the problems of non-communicable conditions also increases, so it is just unavoidable.

And for people that are older, somehow it is going to be the only system that will be workable. That is to say, there has to be integration of dealing with other conditions for people that are living with HIV, as we go forward.

LAURIE GARRETT: Well, Dorothy Onyango, you come from a country that's already facing a budget crunch with HIV/AIDS. Kenya is working hard to figure out how to take on more of the financial burden, itself, to be less dependent on donors. You are not only the current Executive Director, but the founder of Women Fight AIDS in Kenya. WOFAK, you call it?

DR. MONICA ADHIAMBO ONYANGO: Yes, you got it.

LAURIE GARRETT: And, I know that back in the early days of WOFAK, you were looking at, in the mirror and around the room, at young faces. And I'm sure that within WOFAK, you're looking at some older faces today. What we're talking about is not just a distant possibility for Kenya, it's there now. So when you look at your friends becoming grandparents, and trying to cope with the complexity of HIV in a resource scarce country, what do you see down the road?

DR. MONICA ADHIAMBO ONYANGO: Thank you. I think I should start by, myself, it's not about my friends only, it's about myself. Cause when I was diagnosed, I was a young girl of 30. I am now a grandmother of 50, 55 actually, my birthday will be 18th of August.

LAURIE GARRETT: Another congratulations [applause].

DR. MONICA ADHIAMBO ONYANGO: I think what we see, the trend that we are seeing in the community of women that I live with HIV and over 50, I think there seems to be thinking that women who are over 50 cannot engage socially and that they don't have feelings and, as you can see, I'm still sexually active. And, of course, the other women are, so I think we have not had that space for women to be able to engage. Most of the activities of the prevention messages are around those who are between 15 to 49, and therefore, the elderly or actually over 50s, are left out.

I think it's very important that we have programs that target over 50s, and that are able to empower these people—women, especially when they are caregivers, they are taking care of their grandmothers, and when they are able to engage socially, as persons living with HIV.

Secondly, the inadequacies that come with HIV that you cannot actually compare. Is it old age? Is it a result of HIV because we have pre-menopause? Women who are infected with HIV get menopause earlier. What are the symptoms that we would

know that this is a person living with HIV or not? Some extend menopause, and if you not be able—and then there are decisions that come with old age, like dementia, you would not be able to differentiate with it, as a result of HIV, or as a result of old age.

I have heart disease, cardiovascular disease, and this was a result of the side effects of [inaudible 0:48:15], and this also happens to people who age. And, therefore, to deal with the double tragedy of having HIV, and taking drugs for heart disease, at the same time, which is also a life-long treatment, I think it is really a big challenge to pass on to women living with the virus.

Again, the other challenge is that, when you go to a clinic, especially in the rural areas, it is a big challenge, because you are seen as a grandmother and, therefore, they think you would have stopped being sexually active at 49. So if you go to a clinic and the healthcare provider is wondering, what is happening to this granny? Why would she be coming to the clinic for an SDI or for a condom? Because supposedly, you have stopped having sex at that age. I think, even the men in the rural areas, especially in the community, may find that how do you even ask a grandmother to remove her panties so that you can engage in sexual encounters?

There are really many challenges, especially when it comes to old age and you have to talk about your HIV status,

then you have to negotiate about sex, and then you have to negotiate about using condoms. As a person who is over 50, it is really a big challenge.

And I think that is important that more research is also done to ensure that we differentiate that what comes as a result of HIV, and what are the diseases that are there? Because those ones we know, because of old age, yes, it comes. But what are the diseases that come as a result of HIV? And I think more research has not been done, especially in Africa, to come up with exact causes of some of the diseases.

Because HIV has only been with us for 30 years, and therefore, we need to have more research. We need to have more education. We need to empower women to move on with their lives. Because over 50, you can see, I think I look young [applause]. Thank you. Those who are over 50 are sexually active and sexually we need to continue with our lives as people living with HIV, as humans like anybody else.

LAURIE GARRETT: Interesting thing, we had a session on Sunday that I moderated on NCDs, and Peter Lamptey, from Family Health International, told us that one of the things to recall is that, we don't actually know what baseline rates are, of a whole range of geriatrically associated syndromes is sub-Saharan Africa, South Asia, even parts of Central America, and resource scarce countries generally.

He noted that, for example, a survey on hypertension was done in Ghana, and it turned out that 30-percent of the rural population was hypertensive, without controlling for age. Now, if you just took the over 50s, he said it was half the population.

Now, we have a situation where it's not even considered routine, in the delivery of HIV care, in most of sub-Saharan South Africa, to perform a simple blood pressure cuff. So, the practicing physician does not intake with the assumption, well I should make sure you don't have baseline possibility of heart disease, you don't have cholesterol problems, etc. etc.

Now you add to it, how much geriatric care is there for anybody in Kenya? Especially rural Kenya. And if you were to extrapolate from that, and think about your affiliations with women's organizations across the continent, what vision do you have of how the continent can handle this?

DR. MONICA ADHIAMBO ONYANGO: I think, what I would suggest, is that, it's important to work with communities. It is not about the healthcare providers in the hospitals or in the health facility, but we have to reach out to the communities. And, this can only be done by the community health workers, volunteers within the communities, to be able to educate, create awareness and also encourage and refer.

Women, or persons living with HIV who are over 50, to be able to come to the clinic, to be able to get care and

support, and to engage in activities that can support their day-to-day life and also to ensure that—because most of the elderly, taking care of grandchildren of their sons, probably, and daughters who have died. So, they really need support. They need to be empowered to be able to engage and to continue with their lives.

LAURIE GARRETT: Amy, I want to come back to the biology for a moment—or clinical. You started to give us a roadmap based on the Veterans Administration experience, for how to begin to tease out when a patient comes to you. Let me just give you a sort of example that I think would be quite typical.

A man of 55 comes before you. His major complaint is pain on urination, kind of feeling really wasted, tired, and noticing that he's bumping into things a lot and getting bruised. And somewhere along the way, he lets it be known that he's HIV-positive. Now, how in the world, are you going to work up this individual and figure out what is the etiology of each of the things he's complaining about?

DR. AMY JUSTICE: Well, obviously that's a process. It's not something that happens the first visit. I would begin by trying to take a very complete history, as would, I think, anybody in the room who takes care of patients.

I'd want to understand not only what his experience with his HIV has been, but whether or not he has any other

diagnoses. And, given that he's 55, I would certainly ask about chronic diseases, as well as any other infectious diseases.

I would ask about his sexual activity and whether or not he uses protection, and whether or not his partner is aware that he is HIV-infected, and how comfortable he might be with informing his partner, if he has not informed his partner.

I would also do baseline tests that would reflect basic physiologic function, kidney function, adrenal function, liver function. Given that he has easy bruising, I would certainly be interested in his platelet count. And a CBC is a routine count that we would get. And with that information, I would be able to calculate his VAX index to get a sense of how much overall disease burden he may be facing right now.

I would also want to know about behaviors. Does he smoke? Did he smoke in the past? Because, some people have quit but still have increased risk because they smoked in the past. I'd want to know about alcohol use, because certainly alcohol can affect bruisability, as well, and liver disease, as well. I would certainly want to know about Hepatitis C co-infection, because that could have a major place in part.

So, I would try very hard to get an overall profile. I'm sure there are other tests that I would probably think about over time, and once I got back the initial tests, and had a chance to take a complete history, which would include, what

diseases the rest of his family has experienced. You have to take that into account, as well.

Once I had that information, I'd want to sit down and talk with him about what his goals in care are. Let's say that he's actually not that sick, based on the VAX index, but I get some signal that he might have cancer. Because certainly, some of the symptoms you just described, could be warning signs of cancer.

If he's not that sick, based on his VAX index score, and based on my assessment of him, I would want to very aggressively pursue whether or not he had cancer and whether or not he should get treatment for that cancer.

LAURIE GARRETT: Okay, so you've probably now been seeing him for four months, you've had about 10 to 15 office visits, you've ordered up a huge amount of blood-work, you've ordered up urine tests.

DR. AMY JUSTICE: I practice in the V.A., so they have coverage for that.

LAURIE GARRETT: Yes, but I wouldn't be surprised if you've also run either a CATSCAN or an MRI on this individual.

DR. AMY JUSTICE: Probably.

LAURIE GARRETT: So, we're looking at a huge amount of money that's been spent just to begin to tease out what might be causing this individual's problems.

Nils, you've worked in Nepal, you've worked all over the world in resource scarce countries, and you now are, absolutely, one of the top individuals in this country in charge of our global health program. You listen to this and you try to imagine translating this into resource scarce settings? What's the algorithm that a physician, or a community health worker, is going to use to begin to sort these things out?

NILS DAULAIRE: Well, I think this is at the heart of everything we do in global health, is trying to bring as close together as we can, the gold standard, state-of-the-art medical, with the very real resource constraints, both human and financial, that face most of the people living in most of the countries of the world.

I don't think it's a black and white issue. I think one of the things that we as public health practitioners, and researchers and scientists, need to continue to focus on, is identifying which of these various activities and tests have the highest yield? Which ones reflect the public health spectrum in the countries involved?

And to move progressively toward better coverage, higher levels of care, but not to assume that unless we can do everything, we can do nothing. I've seen, in other areas of course, as you well know, even taking simple steps—if you can deal with 40-percent, 60-percent, 80-percent of the burden,

usually you can do that at 10 and 20-percent of the full spectrum costs. So that's really where we need to start.

And I think that there's a lot of terra incognita, in terms of addressing the issues of HIV-positives in older people in low income countries. We really don't know yet, and that's why we're here talking about research, as well as services. We don't know yet what the most important, highest yield activities are, and that's where we need to focus our attention.

LAURIE GARRETT: Should we consider it medical mal-practice to be handing out ARV's without doing blood pressure cuffing? How expensive is that?

NILS DAULAIRE: No, I hesitate to use medical mal-practice as the term, given that there's lots of debate about that in this country. I would say that it is certainly not best practice and it is not the kind of practice we would recommend in even the most basic of circumstances.

LAURIE GARRETT: Should WHO be making recommendations along these lines?

DR. HIROKI NAKATANI: That is a very difficult question because World Health Organizations consist of member states, and now we are discussing – the member states are discussing – what kind of targets or of indicators we are going to set for ourselves. So those are major, major challenges because, I think, many member states feel that let's lead this burden of non-communicable disease, ugly.

Each country has different priorities. Such as, some countries major NCD issue is alcohol; other countries, hypertension; other countries diabetes. So it is quite challenging to have global targets and indicators, but we are working on it. But I think, coming back to you Laurie, I think you said 30-percent of high blood pressure patients –

LAURIE GARRETT: Background; regardless of HIV.

DR. HIROKI NAKATANI: So that is, I think, I have a little bit more insight. That is, to conclude the story, that is only 10-percent – no about – that have a high blood pressure situation. Out of the 10-percent only half is on medication, so that is a huge treatment gap. I think what we learned in HIV response is that treatment and prevention is not contradicting each other.

A treatment as prevention; prevention as treatment. So that kind of dialog we need in NCD as well. NCD colleagues used to be very [inaudible 01:01:47] over primary prevention oriented. To me, it's quite awful. Don't do that; don't eat that; don't drink that. I'm not saying that primary prevention is not important, not at all. It is important, but I think we learned a lot from the response to HIV is that this HIV committee can contribute match to NCD.

LAURIE GARRETT: It's interesting you say only a tiny percentage of the population in sub Saharan Africa, for example, or other resource scarce areas are aware that they are hypertensive and then actually get treated and receive their daily medication to deal with their hypertension. Among the many

posters, and I really recommend that this audience all scour the posters for the indicators of chronic disease associations because it's pretty scary stuff actually, one is a joint Canadian-American study of 230 individuals who suffered sudden cardiac death.

This is not prior indicator; all of a sudden boom, you drop dead. Fifty-seven percent were HIV positive and only one percent of them had a prior history that had been diagnosed of cardiovascular disease. Now this is in resource wealthy countries. What does it mean when you're in a place, as I referred to Ghana, where 30-percent are hypertensive and none of them know it? Ron, I'll let you take that.

RON ROSENES: As I was listening to the discussion, I feel that there's a bit of an either/or between resource rich settings and resource scarce settings. Honestly, in a country like Canada where we live strung out across the southern border for reasons of weather and so on and we have many rural and isolated communities, unfortunately, it has to be said, that we have some communities, particularly amongst our first nations who are really living in third world conditions. Not all by any means, but some, and so I think that some of the solutions and systems that we're looking at in Canada are applicable to both situations existing simultaneously within our country, so not so much an either/or.

To that point, for example, if we're concerned about assessing your cognitive function, the challenge for us that we want to catch it early, and we know that the overlay in aging

with HIV is that often there can be early neurocognitive dysfunction and it can be often described as mild or asymptomatic.

We're conducting research now to look at screening tools that we can have – that will be portable enough to take around the country and so not just people in the big cities, but people in more remote communities or own resource scarce settings can have access to the tools to measure, for example, mild or asymptomatic neurocognitive function. That's just one example of something we want to do. Then we want to look at interventions - including brain fitness programs - that we could also then export via computer and people could use and do within their homes and how do we get medicine out into the communities.

So that's a discussion of that aspect, I think, that has lessons for us in resource rich settings as well as resource scarce; all at the same time. When I listen to the discussion, as well, about the integration of health care, I think about the work that we are now trying to do again to research novel ways to deliver primary health care that make sure that the hypertension is caught at the same time as you're dealing with the HIV.

But I want to remind everyone that as much as integration makes economic sense that we still have to understand that there's stigma attached to HIV. We can't think that we're just going to open the doors of all clinics to all comers and have a success in terms of the way we treat people. It's just not going to work that way quite as easily.

So we really have to think about both the system side and

the way in which we are going to personalize medicine and create sensitive, culturally appropriate settings where individuals can come and really receive a kind of customized treatment program that takes all of their individual needs into consideration.

LAURIE GARRETT: Your warning about stigma really rings with me because I recall in the early days of the AIDS epidemic when we had a dentist in Florida who passed HIV through some procedural thing - we never really figured out exactly what - in his dental practice to some of his dental patients.

The professional medical societies that were the first to jump up and say we want to be able to wear space suits in the operating room to protect ourselves or we want to be able to have mandatory HIV tests of all incoming patients were all surgeons, and for the most part, either cardiologists or orthopedists. So, we could be hitting the point where the HIV population is just hitting that set of specialties in medicine that have had the least to do with HIV. The whole stigma issues will be complex.

Before I open up to the audience, and I would encourage you to migrate to the microphones now if you have a question. I just want to ask Peter one last question. This issue that we don't really have good baseline numbers for at least half the world; if not more.

Is there possibly some way that your department in UNAIDS can be working with WHOs non-communicable disease folks and other epidemiology centers around the world to start to try and figure out what some of those key baseline markers look like so that we're not caught completely off guard when the HIV elevation

happens?

PETER GHYS: Absolutely, but it isn't just the issue of a small department or two small departments in Geneva working together. There is a real issue in primary data being available; or actually not being available. So if we think about some of the data that you were showing – where you showed the progression of the again of HIV in Africa, that is actually based - I was sitting next to the author yesterday – it's actually based on the age that forms one small study in South Africa. For many countries there is actually no specific information about what prevalence is among people of over 50.

So one possible solution to that – or partial solution to that – is to say that the national surveys that have been quite prominent in recent years to determine the prevalence of HIV. Often those surveys limit themselves to the age of 49 for women, and for men they either also stop at 49 or sometimes they go to 59, so that beyond that there is really very, very little information on the prevalence. Then, as we extend to think about incident, where we think about co-heart studies, there are very few of them and the information about what incidents is like in people of 50 and over is extremely scarce.

If we go to the next question, what determines that incidents, it's almost empty space. So there's a lot to be filled, but then, yes, I mean somehow there has to be that work to try and estimate and follow as we are talking about the issue today and recognizing that in the future it will just become bigger. Right? Because people will live longer as they should.

LAURIE GARRETT: This could be yet another way that HIV changes the world. In this case, maybe we'll finally get some baseline data on chronic diseases in many countries.

I notice this side of the room is the inquisitive side. I want to ask you to please be sure to identify yourself and since there are many with questions, actually try to ask a question. Microphone number two.

PAT DALTON: I'm Pat Dalton from New York. I have speculated, and I don't know if there's any evidence or basic science, that aging in newly diagnosed patients is different than people that were diagnosed 25 years ago.

LAURIE GARRETT: That's got to be true. Amy, you want to take that?

DR. AMY JUSTICE: That's an excellent question because most of the data that we have on aging is, of course, from resource rich settings where most of the people that we're studying are folks who've had HIV for 20 or 30 years which is going to be very different than looking at folks with incident disease who are starting anti-virals beyond 50. There's very little data on that group and I would be purely speculating on what the differences might be, but clearly that's a group that we need to begin to study much more carefully.

LAURIE GARRETT: We also have the confounder with the older HIV population in Western Europe and North America that they went through history of mono-therapy, one drug after another, because they were living with HIV through – as Ron was – through the drug invention era. So we have that complicator.

DR. AMY JUSTICE: We do. Although, that is beginning to work itself out; because if you think about when we leveled out on that with respect to resource rich settings - it was around 2002, 2004 - in terms of the differences in mortality that we would see in relation to treatment. So we have a fair amount of information, and people who have had extended exposure to more effective anti-retroviral therapy and fairly minimal exposure to mono – certainly mono – and to some extent dual. That, I think, we're beginning to work through, but this issue of folks who start therapy at older ages is really totally uncharted at this point.

LAURIE GARRETT: Let's go to mic number four please.

LISA POWER: I'm Lisa Power from Terrance Higgins Trust in the U.K., and can I just say, we have a poster on exactly that comparative data on our cohort tomorrow in the poster session, so hopefully you'll take a look at it. I just wanted to raise an issue which I think has been very – you've been very much about physical health – apart from the first gentleman – and when we did our survey of older adults with HIV, we found a lot of mental health issues and a lot of social isolation due to a whole range of things.

I'm sure they're mixed in. I think there's a whole load of things going on around long-term trauma, around uncertainty, around the stigma of HIV, a whole load of reasons. I would be really grateful to just hear some more from the panel about mental health and social exclusion and inclusion; because it's not just about keeping someone alive, it's about getting them a

life.

LAURIE GARRETT: Actually that's a really important point you raised because I neglected to mention that the Office of AIDS Research at our NIH here in the United States just this month released their working group report on aging and HIV. I urge those in the audience to check it out, and they do note that one of the biggest concerns they have is the social isolation of older HIV positive individuals, particularly gay men, because they've often been without family or been shunned by their family and they're approaching really scary stuff on their own. You, Ron, had mentioned this as you felt the overlooked concern for your community.

RON ROSENES: I mentioned the specific issue of depression and the list includes some of the things that you just mentioned. I think that when we work on the issue of aging in community, first of all, some of us prefer to think about it as living long-term with HIV because we're trying to tease out how much of the problem is related to the virus, how much of the problem is related to chronological age and how much of the problem is related to time on medication.

So, of course, then you get the interplay with younger people who may have been on medications from a very early age, and there's a paper here on arterial wall thickness in adolescents who've been on treatment since an early age. We tend though, in answer to your question, to have one group working on the bio-medical side and another group really working on the social services side of the question.

I was listening to an interview in Toronto - where I live – on the radio, and it was from a transsexual Orthodox Jewish woman who was concerned that she would be shunted off somewhere where she would not get the appropriate food or treatment that she wanted given all of those aspects of her individual needs.

So, that just kind of summarizes the tip of a very big iceberg of what we need to be doing in terms of the research to understand the needs that we're going to have from people who want a live-in community to people who want to live in very supportive environments and what all of that is going to need to look like as we try – as we hopefully continue to age and live longer despite all of the physical challenges.

LAURIE GARRETT: Dorothy, I saw you nodding.

DR. MONICA ADHIAMBO ONYANGO: Yeah. I think what I needed to add, that special groups like the groups of people living with HIV which have had so much, especially in psycho-social support, I think needs to be supported.

Then we need to have tailor made programs for over 50s so that they can be able to given information and also to be empowered and be able to follow up on issues of [inaudible 01:15:54], on prevention, so that they don't even infect or get infected because of the lack of information that is there because of the stigma and probably the environment that is not conducive for them to be able to get that kind of information. So I think social groups would really help very much and I think all this needs support. It needs financial and I think this would do a great deal in supporting the AIDS.

LAURIE GARRETT: Can I ask whoever's in charge of it to please turn off this annoying, flashing red light thing. Nils.

NILS DAULAIRE: Just a brief comment. Part of HHS is the Substance Abuse and Mental Health Services Administration, which actually does HIV work outside the U.S. as well as inside. Very often it's the substance abuse side that's viewed as HIV relevant because of injecting drug users, but in fact, they're increasingly working on the mental health aspects of HIV. This is certainly an area where I think there's going to be an enormous amount of both research and implementation work.

LAURIE GARRETT: Mic number two.

FEMALE SPEAKER : Thank you. I want to thank everyone for being here on this panel. This is a very important topic and I hope next year they'll give us a bigger room and won't keep half of us outside. I was able to sneak in. Thank you everyone. I guess my comment is really – perhaps maybe Ron and Dorothy can sort of chime in here.

Dorothy mentioned that there are very few HIV prevention messages targeted for older adults - people over 50 – and indeed, there are very few interventions out there that are targeting older adults. If we could sort of, and maybe perhaps expand it to a psycho-social or a bio-psycho-social perspective, and anyone on the panel can chime in.

What would be some of the things – other than clearly the importance of the mental health issues, depression, etc., loneliness – what would be some of the other variables that we would need to take into consideration in terms of developing an

intervention specifically for older adults; targeting those issues that older adults need? Thank you.

LAURIE GARRETT: Dorothy.

DR. MONICA ADHIAMBO ONYANGO: Thank you very much. I think, just like I mentioned, it's important to have the social groups. At the same time, we need to have tailor made trainings for caregivers and for those who are also over 50 so that they are able to be a – for instance, to get medications, be able to walk freely into the health care facility to talk about condoms.

Come up with social issues that affect people living with HIV and are over 50. It's more or less a social setting that is conducive that they can speak openly just like the youths speak in their own environment, like the people living with HIV who are less than 50 can speak in their own – more or less a psycho-social support group for the aged that can actually empower them to be able to engage.

LAURIE GARRETT: Mic three.

RAYFORD TITLE: Hi, I'm Rayford Title [misspelled?] and I live in Washington. I'm a little embarrassed and kind of ashamed to even mention this because it seems like such a minor thing, but I run a support group for gay men over 50 here and so I speak for others besides myself. I'm 65; I've had HIV over 30 years. I've had both hips replaced; I've got high blood pressure, coronary artery disease, depression; I take 14 pills in the morning and 11 at night, but my insurance pays for a great deal of that.

I'm able to function, I'm still working; I get a lot of

help with that. The thing that is most expensive is to deal with the facial wasting that I have. To get a plastic surgeon to do the injections of the filler that prevents me from looking like a skull, it's very expensive and the insurance companies don't pay adequately; the plastic surgeons won't do it. They say that the insurance companies don't pay for it at the same rate that they pay, for instance, for reconstructive surgery for mastectomies.

LAURIE GARRETT: Let me throw that to Amy.

DR. AMY JUSTICE: I don't have a good answer for that.

LAURIE GARRETT: Ron?

RON ROSENES: I dealt with this in community and I'm entirely sympathetic in the issue. We were about to do a survey in Canada to find out who was still afflicted with facial wasting – lipoatrophy – and it was basically brought to our attention that it was only us old guys who – among the few left with the issue. We've been advocating like crazy to get improved coverage and access to treatment and we were not successful in Canada. There was more success advocating for access in the United States.

I'd be happy to speak with you afterwards and I can direct you to Nelson Virgil's website. Nelson will probably be helpful in getting you to a place where you might be able to access treatment. You'd be able to do so, I'm amazed to tell you, more easily I think in the United States than we are in Canada. Now that medications have changed it's a bit less of a problem, but still it's a huge issue. Thank you for raising it.

LAURIE GARRETT: Well, I'm gob smacked that you can get

it better here than – Microphone number four.

LORRAINE: Hi, my name is Lorraine. I'm a program manager for one of the CSBs here in Virginia. I do HIV early intervention work and I'm also HIV positive; I have been for 23 years. One of the things that I find in my personal experience and from the consumers that I serve is that we all have multiple doctors.

I have neurologist, I have a primary care physician, I have an infectious disease doctor, I have a cardiologist, and largely I am required to go to my primary care physician - who knows nothing about HIV or neuropathy or anything else - for my day to day care.

If I have a neurology - an HIV related neurology thing – I have to see the neurologist who doesn't know anything about my HIV disease. I'm wondering how – earlier you brought up the silo, I think it was, term. How do we get basic care, or if we go to the doctor for blood pressure issues, if the doctor himself doesn't understand my HIV disease?

LAURIE GARRETT: What you're describing is, of course, a problem regardless of whether you have HIV; this total fragmentation of dealing with specialists in health care. I see that Dr. Daulaire – both Amy and Nils want to make comment.

NILS DAULAIRE: Let me just start with some of the changes that are going on in health care under the Affordable Care Act. There are two specific areas that I think relate directly to what you are talking about. They're not aimed at HIV positive patients per say, but it certainly plays into that.

One is the role across the country of the electronic medical record which is designed so that there will be rapid and low friction interface between all the providers so that you don't lose someone's treatment for their diabetes when they go to their cardiologist or, for that matter, their infectious disease specialist. So that's one area.

The other one is that as part of the effort to improve patient outcomes and reduce costs – that's an important part of the Affordable Care Act – there is within the center for Medicare and Medicaid studies [CMS] - or services, sorry [CMS]- a center for innovation now that's looking at ways of bringing together better team work in terms of the care providers; building in incentive systems into the healthcare system so that this will be facilitated; and disincentives, frankly, for fragmented care. This is not the solution to your question, but I think we're at least on a reasonable path.

DR. AMY JUSTICE: You might be interested, there's a session a little bit later discussing the VA electronic medical record system and how it's really revolutionized the ability to coordinate care among specialists. I practice in the VA system. I am a general internist.

I'm section chief of general medicine at the VA hospital in West Haven, and the lovely thing is that we can consult with specialists and have them e-mail us back with any of the medical records, so all the data is there, all the interactions are there. We're all working from one drug list. We're all looking at the same adverse event history. We're looking at the same

allergies. We're looking at the same labs. It hugely helps facilitate this issue. There isn't a doctor, a single doctor or single provider, who's going to know everything that there needs to be known to optimize care for people with HIV and for aging individuals more generally.

We need to learn how to communicate and how to prioritize jointly and to have a whole team. The VA has really embraced the whole idea of the patient centered medical home, which we call patient aligned care teams, where we bring together nurses, physical therapists, Pharm Ds, physicians; the whole team to try to make sure that we've coordinated care, that people can get into care when they need it in a timely way; that they're likely to see their usual providers; that we have a system of coordination and communication which is so essential; to avoid toxic events; to make sure we help people as much as we can; to make sure they get the attention they need.

LAURIE GARRETT: Let's see if we can squeeze in at least one more. Mic three.

AGARDO RUISO: Hi, I'm Agardo Ruiso [misspelled?] from the gerontology department in the University of Puerto Rico. I have a quick question specifically probably for Amy Justice. In aging research there has been a whole epidemiological studies on aging and there has been a lot of interventions developed based on what leads to success.

There have been some people that have started talking about successful aging with HIV. I wonder how close are we to be able to define what successful aging with HIV is in order to be

able to do the epidemiological studies so that we can develop the interventions that are needed?

DR. AMY JUSTICE: Thanks for that wonderful question. I couldn't agree more. There's always been an emphasis, especially in the U.S. on – emphasizing the negative outcomes rather than positive outcomes. I worked with Eva Kahana who was a leader in geriatrics emphasizing successful aging; thinking about exercise, thinking about good nutrition, thinking about staying socially connected with others that have meaning for you and having meaningful activities in your life and how important that is, not only for neurocognitive stimulation, but quality of life, avoiding depression, etc.

I think you could also role that out one step further and talk about non-medical treatments. Exercise is an amazingly effective treatment for all kinds of things. Wasting, right? Anxiety, depression, etc. Hypertension, overweight. So, I think we absolutely need to think about what lessons we can adapt from the geriatric literature and fine tune them for those aging with HIV.

If I may give one example though. One of the things that many of us have started thinking about is the weight gain that happens once people start anti-retroviral therapy. HIV's been known as the wasting disease. For many people, weight gain is an important success sign, and many people overshoot that weight gain.

Even people who begin – who are overweight often continue to gain weight on anti-retroviral therapy and many of us asked is

that a good thing. Or should we start talking to people about not gaining too much weight much like we do with pregnant women at the point that they come in for care.

To counsel them about safe weight gain versus not safe weight gain. We don't yet know whether that's a good idea or not. HIV is the wasting disease. Right? HIV is a chronic inflammatory process. It may be that weight gain has some positive things associated with it. We need to study that and understand whether that sort of counseling is a good idea or not a good idea.

LAURIE GARRETT: Well, I have to say sadly to the remainder of you at the microphones that our time is up. I think we've just started to hit the nitty-gritty and the session could go for another hour. I want to thank all the panelists. You've been fantastic, and to the audience, bravo. [Applause].

[END RECORDING]