Hepatitis C & African-American Women

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Speakers: Hope King Ph.D., MSPH, Camilla S. Graham, M.D., M.P.H., Gloria Searson, ACSW

LEDIA MARTINEZ: Hello. My name is Ledia Martinez, and I'm with the Office on Women's Health. I want to thank all of you for joining us for this timely webinar, African American Woman and Hepatitis C. This webinar is co-sponsored by the Office of HIV/AIDS and Infectious Disease Policy, the Office of Minority Health, and the Office on Women's Health. We are all looking forward to hearing from our three presenters, Hope King from the Centers for Disease Control and Prevention in Atlanta, Dr. Cami Graham from Beth Israel Deaconess Medical Center in Boston, and Gloria Searson from the Coalition on Positive Health Empowerment, COPE, in Harlem, New York.

And now, I would like to welcome Dr. Ronald Valdiserri to share opening remarks. Dr. Valdiserri is the Deputy Assistant Secretary for Health, Infectious Diseases, and Director of the Office of HIV/AIDS and Infectious Disease Policy at the Department of and Human Services. Dr. Valdiserri oversees the implementation of the National Viral Hepatitis Action Plan, our blueprint for responding to hepatitis B and C in the United States. Dr. Valdiserri?

RONALD VALDISERRI: Thank you so much, Ledia. Good afternoon, and I'm encouraged to see that so many of you share our concern about the urgent public health challenge of hepatitis C infection among African Americans. African Americans experience twice the prevalence of chronic hepatitis C infection compared to non-Hispanic whites. In fact, 1 in every 13 African Americans born from 1945 through 1965 has chronic hepatitis C.

We also see death rates from hepatitis C among African Americans that are double those of the general population. This is strong evidence of a significant health disparity, and highlights that we must work harder to diagnose and successfully treat hepatitis C among African Americans.

Today's webinar is occurring at an important time of the year. Next week is National Women's Health Week. Women's Health Week, led by the Office on Women's Health, seeks to empower women to make health a priority by better understanding what steps they can take to improve their own health. We also know that women often serve as the gatekeepers for their families' health care, and so they can play an important role in raising awareness about hepatitis C among their own friends and families.

Today is also National Hepatitis Awareness Month, a time when we work to increase awareness about viral hepatitis and share new information, especially with members of communities that are disproportionately impacted like African Americans. The Centers for Disease Control and

Prevention has many online educational resources that you can use, including a free anonymous five-minute viral hepatitis risk assessment, and email greeting cards that you can send to friends and family members who you think might benefit by discussing viral hepatitis testing with their health care providers. These and other educational resources are available at www.cdc.gov/hepatitis.

Our task is clear. We must increase awareness about hepatitis C, share information about the consequences of untreated chronic infection, and encourage people to be tested and get the care they need. We are fortunate to have more tools than ever before to help address hepatitis C in the United States-- a national viral hepatitis action plan that provides a much needed focus and framework for stakeholders from all sectors to improve viral hepatitis prevention, care, and treatment services. The action plan recognizes African Americans as a priority population because of their health disparities in hepatitis C.

We have many partners inside and outside of government committed to achieving the goals of the action plan. We have expanded coverage for clinical preventive services and care under the Affordable Care Act. We have a specific day, May 19, that has been set aside to promote testing for both hepatitis B and Hepatitis C. And as you will hear shortly, we have new treatments that can actually cure hepatitis C in almost all people who take them.

We're all looking forward to hearing from the presenters we have today. As was noted by Dr. Martinez, we have an excellent lineup of three speakers, and they will highlight important facts and resources that can help us understand how hepatitis C impacts African American women and their communities, and how we can empower these women to address this important public health issue.

Thank you for joining us, and now I'd like to turn it over to my colleague, Ms. Corinna Dan.

CORINNA DAN: Thank you, Dr. Valdiserri, for your opening remarks. In a moment, I will introduce our first speaker. But first, I want to mention that after all three presentations have concluded, we will begin the Q&A period. We are accepting written questions throughout the presentation, as well as during the Q&A period. You can see the question box on the screen now. You can submit your question any time during the presentations, as well as during the Q&A period, using that question box in the GoToWebinar menu.

And now, I'm happy to introduce our first speaker. Dr. Hope King serves as the Deputy Branch Chief for Epidemiology and Surveillance Branch in the Division of Viral Hepatitis at the Centers for Disease Control and Prevention. Dr. King began her CDC career in 1997, and has been instrumental in helping state and local health departments integrate viral hepatitis prevention into HIV, STD, and correctional programs. Dr. King?

HOPE KING: Thank you Corinna. Today I will present the epidemiology of hepatitis C virus infection. What is hepatitis C? Hepatitis C is a liver disease that results from infection with the hepatitis C virus infection. Hepatitis C can either be acute or chronic.

Acute hepatitis C virus infection is a short-term illness that occurs within the first six months after someone is exposed to the hepatitis C virus. Approximately 15% to 20% of people will clear the virus from their bodies without treatment and do not develop chronic infection. Most people with acute hepatitis C virus infection have no symptoms. If symptoms do occur, they may include loss of appetite, abdominal pain, fatigue, nausea, dark urine, and jaundice.

For most people, acute infection leads to chronic infection. Chronic hepatitis C virus infection is a long-term illness that occurs when the hepatitis C virus remains in the person's body. Without treatment, hepatitis C can last a lifetime, and can lead to serious liver problems, including cirrhosis, liver failure, or even liver cancer. Of those who develop chronic hepatitis C virus infection, the most common symptom is fatigue.

So what are the chances of someone developing chronic hepatitis C virus infection, chronic liver disease, cirrhosis, or liver cancer, or died as a result of hepatitis C? If you take 100 persons infected with hepatitis C, for example, we'd know that approximately 75 to 85 of those people will go on to develop hepatitis C chronic infection. And of those with chronic infection, approximately 60 to 70 of those people will go on to develop chronic liver disease. And among those with chronic liver disease, 5 to 20 will go on to develop cirrhosis over a period of 20 to 30 years. And of those who develop cirrhosis, 1 in 5 will die from the consequences of chronic infection or liver cancer or cirrhosis.

So how is hepatitis C transmitted? Hepatitis C is usually spread when blood from a person infected with the hepatitis C virus enters the body of someone who's not infected. Today, most people become infected with the hepatitis C virus by sharing needles or other equipment to inject drugs. However, before 1992, when the widespread screening of the blood supply began in the United States, hepatitis C was also commonly spread through blood transfusions and organ transplants. And although uncommon, outbreaks of hepatitis C have occurred in medical settings, and most often as a result in lapses in infection control.

Hepatitis C can also be spread through sex, although experts believe this does not occur often. However, there is some research that shows that men who have sex with men, people who are HIV positive, and have multiple sex partners have an increased risk for hepatitis C. Lastly, there's little evidence that hepatitis C is transmitted by getting tattoos in licensed commercial facilities. But whenever tattoos or body piercings are given in informal settings, such as prisons, or with non-sterile equipment, transmission of hepatitis C is a possible.

So what is the public health issue? Hepatitis C virus infection is the most common bloodborne infection in the United States and worldwide. However, most of those infected don't know they have it, thereby increasing the risk of developing severe liver disease and transmitting of the virus to others. So what is the global burden of hepatitis C in the world? Based on seroprevalence studies, which are basically studies that look at the blood in the population, we estimate that three to four million persons are newly infected each year, and approximately 3% of the world's population is chronically infected with hepatitis C virus infection, and more than 350,000 people die from hepatitis C virus related liver diseases each year.

As you see from this map, in many developed countries, including the United States, the prevalence of hepatitis C virus infection is less than 2%, which is shown here in the yellow. The prevalence is higher, greater than 2%, in several countries, such as Latin America, Eastern Europe, and the former Soviet Union and certain countries in Africa, the Middle East, and South Asia, as shown here in the orange and red. The prevalence is reported to be the highest, greater than 10%, in Egypt.

Now I'd like to turn attention to what is the prevalence of current hepatitis C virus infection among persons in the United States. In the United States, an estimated 2.7 million persons, or 1% of the US population, is living with hepatitis C virus infection. This estimate is based on the analysis of the blood specimens from the National Health Examination Nutritional Survey from 2003 to 2010. We also know because the NHANES study only captures household residents. We know that residents such as those that are homeless and those that are incarcerated, it's estimated that over 360,000 persons have chronic hepatitis C virus infection.

Also, we know that the burden of hepatitis C virus infection is greatest among those that are born between 1945 and 1965. Two out of three Americans who have hepatitis C virus infection were born between this time period. Persons born in this time period are more likely to be diagnosed with hepatitis C virus infection, possibly because they received blood transfusion before the introduction of screening in 1992, or have a history of other risk factors for exposure decades earlier.

Also, we know the prevalence of hepatitis C virus infection among those born during 1945 to 1965 is approximately 3.5%, which is five times higher than any adult born in other years. The higher prevalence of hepatitis C virus infection among persons in this birth cohort reflects a substantial number of incident infections throughout the 1970s and 1980s, and the persistence of hepatitis C virus infection as a chronic infection.

We also know that males in this cohort have almost twice the problems as their female counterparts. Now, of all the hepatitis C infected individuals in the United States, approximately 81% were born during this time period. We also know that up to 75% do not know that they are infected, so it's important that we know that this time period is very important for those who do not know their status. Lastly, hepatitis C virus infection prevalence was highest among non-Hispanic blacks and males, followed by non-Hispanic white males and Mexican American males.

Now I'd like to turn the attention to the burden of hepatitis C virus among African Americans. Hepatitis C virus infection among African Americans is roughly two times that of non-Hispanic whites. And African Americans account for about 11% percent of the US population, but yet represent 25% of the participants living with hepatitis C virus infection. Also, as mentioned earlier, liver cancer is significantly higher in African Americans compared to non-Hispanic whites.

When we look at African Americans and Hepatitis C mortality rates, we see that in 2010, among patients with hepatitis C virus infection, the highest death rates have been observed among

ethnic minorities, including African Americans. Also, in 2011, the death rate from hepatitis C virus was listed as the cause of death for 7.89 per 100,000 for African Americans, compared to 4.19 for whites. Also, African Americans had the highest mortality rates of liver and bile duct cancer.

As a result, testing is critical to reducing death and disease from hepatitis C. To help increase testing, the Centers for Disease Control and the US Preventive Services for Task Force recommends offering one-time screening for hepatitis C virus infection to adults born between 1945 through 1965. We also recommend testing and screening for hepatitis C virus infection in persons at high risk for infection.

For those that are considered high risk, hepatitis C testing is recommended for anyone at an increased risk for hepatitis C virus infection, which include those born between 1945 to 1965, those who inject drugs or ever injected drugs, even if it was once many years ago, those who may have received blood products made prior to 1987, those who were on long-term dialysis, those with elevated ALT's, those who may have HIV infection, those who were possibly recipients of blood transfusion, blood components, or an organ transplant before July 1992, and persons with known exposures to HCV such as a health care worker who may have had a needle stick exposure to someone who was infected with hepatitis C, and lastly, children born to women with hepatitis C.

In summary, the burden of hepatitis C virus infection is large and growing. African Americans have twice the hepatitis C virus prevalence and mortality as white Americans. Routine testing of persons born between 1945 and 1965 and testing those who are at an increased risk for hepatitis C is needed. If executed swiftly, more HCV-infected persons will be identified earlier in the course of their disease.

However, to improve health outcomes, persons testing positive for hepatitis C virus infection must be provided with appropriate care and treatment. Because new hepatitis C virus treatments have cure rates as high as 90% up to 100%, linking hepatitis C positive patients to care and treatment is a critical component of the strategy to reduce the burden of this disease.

I would also like to point you to resources that you can use later on at the conclusion of this webinar. And I also would like to acknowledge the colleagues that have provided assistance in preparing for this PowerPoint. Thank you very much.

CORINNA DAN: Thank you very much, Hope. I know you have a lot of colleagues at CDC that are doing wonderful work, and really appreciate your presentation here today. We are getting a lot of questions about whether or not the slides will be available. And yes, slides will be available within two weeks on aids.gov. We will give additional information about that later on.

And now, I'm happy to introduce our next speaker, Dr. Cami Graham. Dr. Graham is the Co-Director of the Viral Hepatitis Center in the Division of Infectious Diseases at Beth Israel Deaconess Medical Center, and is an assistant professor of medicine at Harvard Medical School.

Dr. Graham has helped implement electronic medical record prompts for hepatitis C birth cohort-based testing at her own institution as well as at the national level, and helps run a hepatitis C telemedicine program for primary care providers in community health centers in Massachusetts. Dr. Graham?

CAMILLA GRAHAM: Thanks a lot, Corinna. So what I'm going to talk about today is what happens when someone has been diagnosed with hepatitis C. I do want to point out that by the end of this webinar, many of you will know more about hepatitis C than some of the primary care doctors you might go to see. And that's OK, because the goal of this webinar is to help you be able to advocate for yourself, your loved one, or your community.

So you heard Dr. King describe some of the severe complications of hepatitis C. I just want to go over these one more time so we're all sort of thinking about this in the same way. So when somebody has hepatitis C, there's a lot of things that can happen to them. But the ones we really focus on is the damage to the liver. The liver develops scarring, and we're going to call that fibrosis. And about 90% of people with hepatitis C develop that fibrosis or scarring of the liver. Over time, people can develop severe scarring, which we call cirrhosis. And this can take anywhere from 10 to 40 years, depending on the person.

Some of the complications of cirrhosis include it not processing the toxins that it's supposed to process, because everything we eat goes to the liver, which can cause damage to the liver. People more prone to infection. And people can develop additional complications, including liver cancer and liver failure. And some of the problems of liver failure are the buildup of fluid in the belly, which we call ascites, bleeding from large vessels in the esophagus, which we call varices, confusion, which is encephalopathy, or turning yellow, which is jaundice. Obviously, we don't want any of these things to happen to people, and that's one of the goals of our screening process, is to catch them before they develop severe complications.

So you heard about how Baby Boomers, people born from 1945 to 1965, are at a higher risk of having hepatitis C. Many of these people were infected 20 to 40 years ago, and they've hit that time of infection that makes them at increased risk for developing cirrhosis and severe complications. In fact, about 25% of those Baby Boomers already have cirrhosis right now, including people walking around who have no idea that they even have infection with hepatitis C.

About 75% of the people with cirrhosis are men, because men don't do as well with cirrhosis. So this is a focus on African American women. The 25% of people who have cirrhosis that are women run into trouble with it. So I do not want to imply that women don't have a problem with cirrhosis or complications. They do. But women also have husbands and fathers and uncles and other men in their lives that they can help advocate for, and I want you to keep them in mind as well.

Because of how long these Baby Boomers have had hepatitis C, the peak of liver failure and liver cancer is going to be around 2020 if we don't immediately start working to identify people

and get them into care and treatment. Now, you've already heard that African Americans have a higher rate of liver cancer and a much higher rate of all-cause mortality compared to other racial and ethnic groups with hepatitis C.

So when I first have somebody come into my office who's been newly diagnosed with hepatitis C, I frequently get questions like can I hug somebody in church? Can I bring food to a community gathering? Can I take care of my grandchildren? And what I want to emphasize is the answer to all of those questions is absolutely yes. Hepatitis C is not transmitted by casual contact-- not by hugging or kissing or sharing food or water or utensils, or any other casual contact. It's shared by very small amounts of blood. It could be blood on a toothbrush or a razor or clippers, which is why all of those items need to be kept in a separate kit if you know that you do have hepatitis C, or someone in the family does.

I mentioned the toxins. The liver can't process drugs and herbal products as well, and they can sometimes hurt the liver. So every single thing someone takes needs to be reviewed with a doctor or other health care provider. If people have not been exposed to hepatitis A or B, they need to be vaccinated.

For those people who are currently using illicit drugs, especially injecting, they need to try to get into rehabilitation or addiction services. If they're not ready to stop, not willing, not able, then they need to absolutely not share needles, cookers, water, anything else that might be contaminated with even very small amounts of hepatitis C so they don't get new strains of hepatitis C and they don't transmit to others.

In terms of sexual relationships, if somebody's in a monogamous, heterosexual, long-term relationship with somebody who maybe doesn't have hepatitis C and this person does, the risk of transmission is extremely low. It's estimated about 1 per 190,000 sexual contacts per year, which is a lot of sex. Where we do see sexual transmission is in new relationships, young women, men who have sex with other men. Those groups need to use condoms.

In terms of alcohol use, the easiest thing to keep in mind is alcohol doesn't mix with hepatitis C. It's like fuel on the fire. So for most people, it's better to avoid alcohol. We especially emphasize that in people who already have developed moderate or more severe levels of the liver scarring. I do want to remind women that we don't process alcohol as well as men, and so more than one drink a day of alcohol is actually too much for women. It can damage the liver, with or without hepatitis C, and it's much worse if people have hepatitis C.

Another question I frequently get is from people who've maybe been diagnosed for 5 or 10 years, and they've been hiding from the hepatitis C treaters because they don't want a liver biopsy. And the first thing they say is if you're going to make me do a liver biopsy, I don't want to even talk to you about treatment.

These days, it's very unusual for us to have to do a liver biopsy on people. We've got special blood tests that we can do that give us a very good sense of how much scarring someone's liver

has. There's certain things that we look for on physical exams. And there's a device called FibroScan, which is kind of like an ultrasound, but the sound waves help detect how stiff the liver is. And it's a very good way to see, again, how much scarring somebody has. It takes 15 to 20 minutes. It doesn't hurt at all. It's like an ultrasound. And more and more cities and hospitals are getting these tests.

So why do we want to find people and get them into care? Because ultimately, we want to get people on treatment, and we want to cure them. Dr. Valdiserri already said this, but I'm going to emphasize it. Hepatitis C is curable. Unlike hepatitis B, unlike HIV, you can completely eradicate this virus from someone's body with effective medication. And when you do cure that person, even someone who already has cirrhosis, you dramatically decrease the likelihood that they're going to get liver cancer or liver failure, or even die in general. It decreases the likelihood that someone's going to die. So that's why we're trying to treat people.

Now, another thing I'll hear is treatment doesn't work in African Americans. And if people are referring to the treatment that we had before 2011, they are absolutely correct. Back then, the pegylated interferon, which is the shots and the pills of ribavirin, only cured about 20% of African Americans. If you lined up 10 people and treated them all with these shots of interferon for an entire year, only two of those 10 would be cured. That's discouraging, because those were tough treatments to get through. Even with the first generation of medication that we added to the interferon and ribavirin, the direct-acting antivirals, because it still had to have the interferon, it did not work as well in African Americans as it did in Caucasians.

We discovered around that time that African Americans are more likely to have a gene that makes their cells less responsive to the action of interferon. It's a genetic difference that made the cure rate so much less, and that was specific to the interferon. So now we have pills. The first one I'm showing is the popular ledipasvir, also called Harvoni. And then there's another one called 3-D, or Viekira Pak, that people take from eight to 24 weeks. You can see on these red and blue bars that the cure rates are essentially identical between African Americans and Caucasians. This is the first time in history that we've had this, and these cure rates are over 95% in most patients that are being treated.

So just to emphasize, the old treatments of the injections for a year with lots of side effects and lots of people not even being able to get on it, that no longer is the case. We now have very high cure rates. It's pills, 8 to 24 weeks with few side effects, and most people can, theoretically, be treated.

The two main regiments we use now are called Harvoni and Viekira Pak. There's a little bit of differences that might make us choose one versus another for patients. Most of the time, the choice is made by which insurance company covers which one. Viekira Pak is a little bit more complicated to take. It's more pills. But both of them are very good with high cure rate.

I wouldn't be able to talk about hepatitis C and treatment, though, without addressing the issue of the cost of the treatment. Anybody who's read anything about hepatitis C knows that these

treatments cost a lot of money. And what this has created is an atmosphere of, I would call it almost hysteria around this issue. It's caused confusion and doubt among providers about who it is we should be trying to treat. There's been hesitation to encourage testing by primary care doctors and health departments and other organizations because they don't want to find people and then not be able to get them into treatment. The payers are concerned about budget impact. We've actually seen a lot of rationing of treatment, and I'm going to talk about a couple of the rationing strategies that have been used, which has also created conflict between patients and providers and the payers.

We're not talking about cure as prevention, how we're going to eradicate this disease in the United States as much as we should. The thing that probably makes me the saddest is people who already are disenfranchised, already maybe feel stigmatized or judged about their hepatitis C. These discussions reinforce that maybe they aren't worth treatment, and that's absolutely not the case. And ultimately, we've lost an opportunity to use these transformative curative therapies to try to change the dialogue about what we want, how we want to eradicate this disease.

I want to emphasize the cost per cure is no different than what we've been paying for the last 13 years. These are not outrageously more expensive than what we've already been paying. The problem is there's a whole lot more people who we now are able to treat.

All right. There's a couple of things that are restrictive that I do want to emphasize because I don't think that they're appropriate. One is not allowing people to be treated until they already have advanced fibrosis. One of the problems with that is our tests aren't perfect, so you're basically saying, we really only want to treat cirrhotic patients. And if you're forcing people to wait until they have cirrhosis, you've now told them that they have to get screening for liver cancer every six months for the rest of their lives. Because even though the liver cancer risk is decreased by about 80%, it's not zero. There's still a risk if somebody's developed cirrhosis. If I can treat somebody who's only got mild or moderate fibrosis and cure them, then they go back to the general population of people who never had hepatitis C, and I think that's ultimately the goal that we want.

The other problem is restrictions based on substance use. So people who have recent either alcohol or other illicit drug use are being told that they can't be treated until they have six, or maybe even 12 months of sobriety. Our Veterans Administration has empathized there are no published data supporting a minimum length of abstinence as an inclusion criteria for treatment, and that patients with active substance-use issues should be considered for therapy on a case-by-case basis, and care should be coordinated with substance-use treatment specialists. This is what everyone should be following.

So I've also put up some resources that can be helpful, including federal guidelines. The VA guidelines are fantastic. The hepatitis C guidance by the professional societies gives very specific details. And then I work with the National Viral Hepatitis Roundtable, which has a whole bunch of resources that can help with advocacy and education. Thank you.

CORINNA DAN: Thank you so much, Cami. And now, I'm happy to introduce Gloria Searson. Gloria is the Founding Director of the Coalition on Positive Health Empowerment, COPE, which provides hepatitis C advocacy, education, and preventive services in Harlem and The Bronx. With more than 22 years of experience in HIV and HCV services, Gloria is a leader in engaging African Americans and women in HIV and Hepatitis C advocacy. Gloria?

GLORIA SEARSON: Hi. Thank you guys so much for having me, and I hope that I can add to this discussion around the excitement of these new hepatitis C curable medications, and also share in on all of the great things that Dr. Ron Valdiserri, Dr. King, and Dr. Graham spoke about.

I first want to just mention something about what Dr. Valdiserri said and sort of lead my discussion around that. He started out talking about how African Americans are disproportionately affected by yet another disease. Right there, we may lose some attention. We're used to hearing that no matter what the disease is. So I'm really happy that we're having this discussion and we're specifically targeting African American women, because I believe we have a huge opportunity with these curable diseases with all of these resources that we have around awareness, education, and testing, that they could be leaders in helping us get to the eradication of hepatitis C in African American communities. So thank you for that.

We talked about all these amazing breakthroughs. I've even heard someone refer to as "The Golden Era." Doctors [? Dietrich ?] and myself have been touting it as the beginning of the end of hepatitis C. So of course, most of us that have been working in this field for a long time, we're really excited. We did not expect this.

And I want to say personally I'm excited because I'm everything that both Dr. King and Graham outlined would not have been cured with the previous treatment. As a matter of fact, it wasn't even recommended for people like me. I fit the total characteristic of everyone that the previous drugs were not going to work for. So I'm excited to say today that I'm a living testament that the medications work. I'm cleared, I experienced very minimal side effects, and I'm happy to say that I'm seeing in my work that eight out of 10 people getting cured, and it's regardless of race or sex. And that's not something I was able to share in the past. So thanks for that.

There's a "however" here, and I really want to emphasize that we have an opportunity, and we didn't anticipate where African American women stood when we set out to do the work that we did, but it does bring up some interesting thought about why and who they are that are infected.

So African American women are part of the Baby Boomer population. Why is that important when we speak about African American women and Baby Boomers? Let's go back to the years we're talking about-- the '40s, the '50s, the '60s-- segregation, poverty, urban areas, a lot inter-generational socializing, the way we were raised in our family. Potentially, the risk factors that we were exposed to we didn't even know were risk factors. The way in which we lived our life put us at risk long before we even had a chance to fight or protect ourselves from something

like hepatitis C. We are part of the birth cohort, the times were different, and that's why we're seeing a lot of women in this field, and men, from the birth cohort in African American communities.

There's a lack of knowledge about it. There was certainly a lot less information back then. But today, we're good candidates for treatment, because women are not someone that we have to just pull out and say that they can't treat this for whatever their personal reasons are.

So I want to start with this and say it might help talk about what we want to talk about today. The reason COPE was founded is that I'm a person living with HIV and hepatitis C. And when I started looking at all the data that was coming out, I was so excited that I went and I told everyone, especially in the rooms of recovery that share the same illnesses as I do, about what was coming, how we needed to get prepared. And together, we founded COPE in 2010. And we put together this model that works, that knows how to engage people, that educates them, that teaches them how they need to advocate for themselves and speak up, how treatment can be prevention from them thinking about putting themselves at risk.

Some interesting stuff has happened while we've tested. In the past 2 and 1/2 years, we tested over 3,000 people, and our data provoked some interesting opportunity for us with the hepatitis C infection around race and gender. As you can see here, we've tested 3,044 people from 2012 through 2014. And we didn't go out looking for African Americans specifically. We looked at highly dense areas that were heavily impacted with Hep C based on the city and state surveillance, the little that we had, and we targeted those zip codes.

And interestingly enough, we found that women more than men, and African American women specifically, were more likely to stop and engage us around what we were doing. And when we informed them about hepatitis C, they were able to understand and comprehend that information. And even if they didn't think it was for them, they understood their role in bringing it back to the people in their community that they knew where potentially infected with this disease. And they, then, let those people to COPE, and we've now put over 300 people into care. And they're somewhere on the continuum with 34 cures since 2012.

So this side is just to show, overall, one of the things that we did notice was that African American women, they had a lower prevalence than African American men with seropositivity, but they were more likely to test, more likely to act on doing something, even informing their community, their loved ones. But then when it was them, we had some blocking, and that's what I'll talk about in the coming slide.

When we looked at what was in the way of African American women, it wasn't what we thought in terms of what all the data was saying-- they weren't insured, they were disproportionately marginalized and not in health care systems. We found the contrary. We actually found that they were in care, they did know their status, but they didn't understand what it meant to have hepatitis C. They weren't given any instructions on how to live with this disease.

And so when we educated them about that, they were like, what, and why hasn't anyone told me not to drink, not to eat fatty foods, not to do-- I mean, even if you think they might have known that, I think the proactive thing was noticed right away. We can reach them. We can engage them. So I just put up this diagram on this chart to show you that one of the interesting things that I'm seeing with COPE is that yes, we can diagnose them, but if you look at what [? Ushea ?] has in her slide, it's like we are seeing 9% after the SVR. And it's really, what are all the things that are happening in between? We do the confirmatory, so if you're starting to work with people who are marginalized, who may need nontraditional ways of doing things, it's a great way to get these things done without putting them in the traditional health care system before they get to the health care system. And we've seen that that has more success. And our chart is more evenly divided, and we have a better percentage to SVR.

So what are the barriers? They're not unlike barriers for anything. I really don't want to generalize when it comes to African American women, like we are not able to do certain things, like we lack education or we lack something. It is what is available to us and how we're able to prioritize it with our own resources, and has anyone really put forth a real diagnosis to help us with whatever psychosocial barriers or worrisome things that are in our life. We don't necessarily see Hep C as the thing we should be dealing with. Even if we've been told everything, even if we're in a doctor's care, even if a doctor's offered us treatment, I've seen a lot of ambivalence with women versus men.

And then with African American women specifically, there's a lot of mistrust. And I don't think we're doing a good job of talking to them if they didn't enter the system telling us about their previous history with alcohol, substance abuse, that we engaged them in a very culturally sensitive way with the respect that's needed for them to make the necessary changes. And if they've been on previous treatment, I think these are the hardest people to convince, as Dr. Graham said, that no, it's not the old meds, no, things are different, and yes, there is going to be some potential positive outcomes, not just for your liver, but your overall quality of life in general.

What we found is that it's better to do individualized treatment plants. Maybe it's our social work mentality. Maybe it's the fact that we believe in motivational interviewing. We believe in removing whatever is blocking you from your, in this case, cure or whatever blessings you would get from getting into some good care, getting with the right doctor who understands you. We need to be able to have women-- specifically, African American women-- be able to be open about what may not be an ideal situation in their life and not be judged by that. And I think we'll be open to saying, yes, I am infected. Yes I have done this, No, I'm not doing what I need to do. I think we don't go in putting another scar on our plate. And we have to address the stigma, and we have to give people a reason, what I consider plausible deniability, to say, I have it, I'm going to get rid of it. I understand that people may judge me based on this.

And the other thing that I've found specific to African American women is that we need to tell them, I know it's challenging. Every process throughout the continuum may cause a lot of challenges or more work for someone to do. So my care coordinator, I often hear her say, you

know what, I'm going to ride this out with you. If you're having trouble, say, with the insurance part, communicating with your doctor, wherever they sent you to do your FibroScan-- all of that, I'm going to help you.

One thing that I really want to emphasize here is I've found that no matter what in terms of a diverse population, even within African American women, they're very diverse as well. But the interesting thing is that when you really put in front of them what are the trade-offs versus the benefits, they always choose the right choice. So I think we have to really pay attention.

African Americans can be a huge political force. I think we need to take this opportunity to bring the education, bring the advocacy tools, put them in a position to advocate. Maybe we don't know the role that they play in your communities or in our communities, but they play a huge role. They have all the politicians. They know them. They work the polls. They have a huge opportunity to reinforce some of the legislation that we're trying to put forth. But we need to engage them. I've been working in this field 22 years, and I have not seen any African American involved at the level we need to, and we need to get them involved. And we need to arm them with all this information.

So Dr. Graham, she did a great job of breaking it down. I mean, we can't leave this call being OK with any restrictions. We can't leave this call feeling like doing the prior authorizations or something we don't want to put up with to get people cured. We need to do whatever it takes to get cured. We need a government national response. We need funding. And we need all of us to get on board. And we need to involve the diverse population that's infected. And we need to not put in the generalized ways and really tie this so much to behaviors, because the African American women that are living with hepatitis C today are probably not living the way they were when they were infected. Thank you so much for your time.

CORINNA DAN: Thank you, Gloria. And thank you Hope and Cami also for your very informative presentations. I also want to thank those of you on the webinar today. We have an amazing showing, so I appreciate your time and attention to this important health issue. And now we will have a question and answer period. Please remember that you can type your question into the GoToWebinar box question box. And I guess we've had a lot of questions already coming through. But Hope, one of the first questions I'd like to ask you-- I think you touched on this pretty well in your presentation, but we still had some questions about why people born between 1945 and 1965 have higher rates of hepatitis C.

HOPE KING: OK. That's a great question. And I went over that a little fast given the time. So let me just go back here one moment. Basically it's based on what was going on in those time periods of folks that were born in that birth cohort, which again, is 1945 to 1965. So preceding that time period, a lot occurred in the 1970s, in the 1980s in regards to health.

So at the time, we didn't begin to screen the blood for hepatitis C until after 1992. So there might have been incidents in that regard. So that one--

RONALD VALDISERRI: This is Dr. Valdiserri, Hope. I think that's adequate. I would just underscore in case people didn't catch this, it wasn't really until 1989

HOPE KING: --'89--

RONALD VALDISERRI: --that the virus was actually described and identified. And so prior to that time, as you said, there was not a way to diagnose it. And some of those transmissions were probably related to health care setting encounters, some of them obviously related to injection drug use. So what's our next question?

CORINNA DAN: OK. So Cami, I think you have some information that might help answer this question. What's your experience? Why are death rates from hepatitis C higher among African Americans than among other populations?

CAMILLA GRAHAM: We definitely need more research on this area. Because there are some biological differences, and that may be similar to the biological differences we've recently discovered around how well people respond to interferon and the other treatments. There's just access to care. So just as African Americans have poor outcomes with diabetes, with heart disease, with many, many other diseases, access to specialists, access to liver transplants, access to the kinds of testing that we do to follow people for liver cancer-- I think a lot of it is in access, and some of it's probably biological risks. And we need to figure that out, and we need to overcome those barriers.

CORINNA DAN: Thank you Cami. We've had some questions. People are a little confused about the differences between hepatitis A, B, and C. I don't know if any of the presenters have a nice, easy way to remember? Maybe Cami, if you want to start just how folks can understand the differences between especially hepatitis B and C, but A has been asked about as well.

CAMILLA GRAHAM: Yeah. So hepatitis A, the risk is from food or water. That's the one that you'll see outbreaks with contaminated strawberries or other fruits, other foods. Chili's restaurant a couple years ago-- not to malign them-- had an outbreak, and that's when people have unsanitary conditions like a food worker not washing their hands. So that's hepatitis A. There's a vaccine that prevents it. You get it once, and then you clear it, and there's really no chronic disease.

Hepatitis B. In this country, 95% of our new cases of hepatitis B every year are people who emigrated from countries where there was high rates of hepatitis B. In most of the world, the transmission is from mother to child or as children or very small children, they get their hepatitis B. And then most of the time, it's when they emigrate to this country.

Within this country, we've almost eliminated hepatitis B in our youth, people maybe now under about 20, through our vaccination series. If you've had a baby in the last 20 years, you know that one of the first things they did was get a hepatitis B vaccine. Adults that are still at risk, it's mostly sexual transmission. It's injection drug use. This group makes up about 5% of our new

cases every year. If you get it as an adult, about 95% of people will control the virus, will immune control it, and about 5% will go on to chronic infection.

Hepatitis C is mostly bloodborne. I agree with Dr. Valdiserri that a lot of that transmission occurred from interactions that happened, whether health care or in the community with shaving and things, before we implemented universal precautions for HIV transmission risks in the late '80s that ended up also decreasing hepatitis C transmission. The majority of people with hepatitis C that are exposed will go on to chronic infection. It's a slow and insidious disease that slowly damages the liver.

The problem is we've already had that slow period. We've already had many people with 20 to 40 years of that ongoing fibrosis, which is why we're seeing so much cirrhosis now. And there's no vaccine.

And the other thing that I think we haven't emphasized that is important is if you've only gotten an antibody, you have not been diagnosed with your hepatitis C. About 50% of people in the United States have not had a viral load done when their antibody was tested. And you have to have a viral load done after the antibody is positive to see if you actually have the virus inside you, active infection, and not just evidence of prior exposure. Because some of those people will have cleared it themselves, and they don't need anything. They don't need treatment.

RONALD VALDISERRI: This is Dr. Valdiserri. One other point for the non-medical audience, these are three very different viruses. I would say that Dr. Graham explained how they present. They are different viruses. We call them all hepatitis because they all damage the liver, but they're three different viruses with different manifestations that Dr. Graham went over.

CORINNA DAN: Thank you. Thank you both. So Gloria, maybe you could help to answer this. What have you been able to do when insurance denies medication that's recommended for one of your clients? Have you been able to help some of them to access the medication? How has that worked for your clients?

GLORIA SEARSON: Well, we have developed a template letter that we received from a couple of doctors that have been successful. We've shared that with the patients to bring to their doctors when they receive the denial letters. We also worked closely with the PAP programs. We provide education about them so that if the doctor they're going to see doesn't know.

But generally, we have a great relationship with the doctors we're referring patients to. We become the assistance they need if they need it. The specialty pharmacies have helped play a role sometimes. But we have just really been the person that does the work with them, help the doctor get all the supportive information to the insurance company. And we've even had to switch people's insurance, if necessary, to make it happen. And that's just the truth.

CORINNA DAN: Great. Thanks for sharing some of your experience and strategies to help people access hepatitis C medication, Gloria. Understandably, because we've got a great

audience of women who are concerned about this, we've had a number of questions about perinatal transmission of hepatitis C. And I know that Hope mentioned it briefly that perinatal hepatitis C transmission does occur, but it is rare. It happens not very often, I think 7% or so of the time among women who have chronic hepatitis C infection. But maybe Cami, are you aware of any way to prevent mother-to-child transmission, or whether or not hepatitis C infection has any effect on the infant, on the fetus?

CAMILLA GRAHAM: Yeah. So what I do, I treat a good number of young women who would like to have babies and who aren't willing to face a 5% transmission risk-- because that's one out of 20. If you're the mom and you're facing a one out of 20 chance of passing hepatitis C on to a baby, for some women, that's too much. So women who aren't immediately needing to get pregnant, maybe they're younger, we really encourage them to go ahead and get treatment and get cured. And I've, frankly, had very good success with insurance companies when I-- they might deny them because they're young and they don't have any liver scarring, but when I emphasize this is to decrease the risk of transmission to the baby, I've been successful getting the medicines covered.

For women who are already pregnant, these medicines are class B, but I don't know anyone who's trying to treat women during pregnancy right now, because it's tough. You would just be devastated if something actually happened to that baby. And since it hasn't been studied, we just don't know.

So usually, once women are pregnant, then we just say go through your pregnancy. There's certain things that are done or not done during labor, and any OB/GYN who's informed of the status of the mom, that she has hepatitis C, will know how to implement the things to reduce the risk of transmission. Things like cesarean section don't make a difference. Women can breastfeed when they have hepatitis C. So we need more research on that. But at the moment, what I really try to encourage women to do is go ahead and get tested and get treated before becoming pregnant.

CORINNA DAN: Great. And what does class B drugs mean, Cami?

CAMILLA GRAHAM: So class A means that you've got human data that says that it's absolutely safe. And there's very few medicines that are class A. Class B means they've been studied in several different animals who've been pregnant during the research and haven't had any problems, but we don't really know anything about what would happen in humans. Class C means there's been some signals in animal models that maybe there's a problem. And class D means that drug actually hurt the fetus, hurt the baby, and you should never use it.

So when we have class B drugs, lots of antibiotics are class B. Some of the HIV meds are class B. We could theoretically use it, but we're balancing the risks and benefit. And usually, we're really focused on not harming the baby.

CORINNA DAN: Great. OK. Thank you Cami. So Hope, there are a couple of folks on the line who are asking questions about who do we contact or how can we get involved to set up a hepatitis testing day. Are there resources to help folks with that?

HOPE KING: --question. I would point to checking with your state or local health department first. Throughout the nation, we have adult viral hepatitis prevention coordinators that are stationed in your state and local health department that can help you navigate whether or not they are sponsoring a hepatitis testing day, awareness day, in the month of May in particular, and then when we go through World Hepatitis Day in July. So that would be my first advice.

If you're having problems finding that person, you can go to our CDC website, which is on my resource page, and the adult [INAUDIBLE] prevention coordinator name and contact information is listed there also.

CORINNA DAN: Great. Thank you Hope. You've provided the CDC's hepatitis website, but I believe that there are a number of other resources available for folks who'd like to do a testing day. I know every year in May there is a hepatitis testing event calendar. So if you aren't looking to do a testing event yourself but you're looking for a testing event nearby, you can look them up. If you are doing a testing event, you can register your testing event there so other people can find it by searching by city or by zip code. And I believe there are some other resources on that website as well that can help support organizations that want to get into the business of hosting a hepatitis testing day. So that's wonderful.

GLORIA SEARSON: Can I just add that July 25 has been designated as the African American Day of Action for the prevention of hepatitis C. And we are very interested in partnering with people around the country to have simultaneous events going on for that day. So if you want to reach out to COPE, we would be happy to help set things up with you for that.

HOPE KING: I would just also add, Corinna-- this is Hope-- that if you go to our CDC website for the division of viral hepatitis, which is on our resource page, we also have a national map that shows the test day event. So you can click right on your state and pinpoint whether or not there is a testing event going on, and you can also add your information into that as well. So I would encourage all to use the resource link from this webinar to find out what's happening in your local area.

CORINNA DAN: Great. Thank you Hope. I just wanted to highlight one other important resource that Hope mentioned just a couple minutes ago. There are hepatitis prevention coordinators in almost every state as well as several large cities. And again, on that CDC website, there is a list of those coordinators.

So if you are looking for someone in your state who knows what's going on with hepatitis, is hooked in to all of the CDC resources, those CDC-funded viral hepatitis prevention coordinators are listed on the CDC website and are wonderful resources for community-based organizations, health departments, faith-based organizations, and others who are looking to do more with

viral hepatitis, and to network. Because we know that we cannot do this work alone, that we really need to partner and network and work together to elevate the issue, to raise awareness, and to get more information out there.

We've had a couple of questions about HIV and hepatitis C. The first was around drug-drug interactions. And Cami, since you're the infectious disease specialist, perhaps you could answer. Are there drug-drug interactions among the medications for hepatitis C and HIV?

CAMILLA GRAHAM: There are. And it would be a little bit complicated to try to get into them on this call, but if you're going to hepatitis C treaters, it's different than your infectious disease doctor. It's important for both of them to go and look up the information-- the companies have them in their product labels-- to make sure that the regimen that you're on is completely safe to take with the hepatitis C regimen that you're on.

Some of them, we will keep the people on a particular HIV regiment, but we'll just have them come back a little bit more frequently and monitor them more closely. And the particular thing that we're worried about with a lot of the interaction is kidney function. But actually, Gloria might have some good insight too, though.

GLORIA SEARSON: One of the beautiful things we can talk about now is that being coinfected was a barrier, having Hep C. We didn't know what to treat first in the past. Now, it really doesn't seem to matter if you are coinfected.

I will commend the pharma companies for trying to do their due diligence around checking the drug-drug interaction for the most used HIV meds. And it appears as though they've done a good job, at least well enough to guide the doctors on how and what choices you have and not interrupt your HIV care. So I really don't think it's as much of a problem, and that's one of the additional reasons for us to be really excited for these new drugs.

CORINNA DAN: And Gloria, we just got another question in that's specifically for you. For women who have HIV and hepatitis C who are African American, how likely are they to participate in hepatitis C treatment?

GLORIA SEARSON: Well, that's where we saw the ambivalence. But I do believe that they're just sitting around waiting for the appropriate time. So just one example of a patient who did not successfully get cured with one of the recent treatments was offered retreatment-- she has not not shown up. She's not not participating, but she is taking a little longer to get back on board with the new treatment.

I think it's really about how we can get them to prioritize it, how we can emphasize that three months will go by so quickly, and how we can be of support to you through this time and that the limited side effects are going to help. As long as we can remove the barriers in accessing the care for them, I think it'll be truly important.

And one of the things we can really use to help them is the complications. They do not want to end up with those complications. So if you can push that, I think it'll be easier to get them to treat. It may take a while. Everybody's different.

CORINNA DAN: Great. OK. Thank you, Gloria, for sharing some of your experience with us. So we've also seen a couple of questions about the Affordable Care Act and whether or how the Affordable Care Act might affect people being able to access hepatitis C treatment. And I wanted to just briefly say that, as most of you are aware, the Affordable Care Act has really become very complex.

The great thing about the Affordable Care Act is that it made it impossible for companies to exclude patients based on preexisting conditions. So many people who had the chronic hepatitis C or hepatitis C in the past were not even able to get health insurance because of their preexisting condition. And the ACA makes it possible for those people now to be insured.

The other thing that the Affordable Care Act does is it requires new health insurance plans to cover screenings that the US Preventive Services Task Force has given an A or a B grade to cover those without any co-pay required from the patient so people don't have to pay extra. And hepatitis C testing is one of those recommended preventive services that has a B grade. And so people should be able to go to their primary health care provider and ask for a hepatitis C test and not be charged any additional money.

And actually, those preventive services also include hepatitis A and hepatitis B vaccines. So people should be able to request those, and they should be covered because of the Affordable Care Act.

There have been challenges with both accessing hepatitis C medications after the expansion of Medicaid in some states, but that is really a state by state question, and it's a little much to get into on this call. So I would recommend, again, reaching out to your viral hepatitis prevention coordinator and/or to other advocates in your state and your state Medicaid program to learn whether or not those medications are on the formularies and accessible to folks that are on those health insurance plans in your state.

But I see that we are almost out of time now, and it's been a wonderful hour and 15 minutes. I want to, once again, thank our presenters. I also want to thank our co-hosts, the Office of Minority Health, and the Office on Women's Health. And I'm thrilled that we've been able to present such meaningful information really specifically targeting African Americans and hepatitis C, because that's really been a major gap in the past.

I want to thank the participants that have joined us and stuck it out with us through the whole webinar. I hope that the information that we shared has given you some ideas about how you can join in efforts to increase awareness about hepatitis C in the African American community.

One last question that I'd like to respond to. Someone wanted us to repeat the date of the African American Hepatitis C Action Day. That is July 25 every year, and Gloria referred to the COPE website will have more information, or you can contact COPE to get more information about the African American Hep C Action Day.

But really, I hope that you will all consider how you can join in efforts to increase awareness about Hep C in the African American community to get people tested, get them into care, encourage them to look into whether or not they want to be treated. Because by working together and sharing information and resources, we can eliminate this health disparity and save lives.

Thank you for your time and attention this afternoon. The slides and the archive's recorded webinar will be available at aids.gov/hepatitis within two weeks. Thank you.