Challenges of being older and HIV positive amid the pandemic

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Featured topic and speakers

In recognition of National HIV/AIDS and Aging Awareness Day, AMA Chief Experience Officer Todd Unger (he/him/his) talks with three experts about the challenges older, HIV-positive individuals are facing during the COVID-19 pandemic and the work they’re doing to combat those challenges.

Learn more at the AMA COVID-19 resource center.

Speakers

- Magda Houlberg, MD, chief clinical officer, Howard Brown Health
  - Pronouns: any with respect
- Bill Gross, assistant director, special programs, SAGE
  - Pronouns: he/him/his
- Jill Dispenza, director, HIV & STD resources, Center on Halsted
  - Pronouns: she/her/hers

Transcript

Unger: Hello, this is the American Medical Association's COVID-19 Update. Today we’re discussing the challenges of being older and HIV-positive during the pandemic in recognition of National HIV/AIDS and Aging Awareness Day. I’m joined today by Dr. Magda Houlberg, chief clinical officer at Howard Brown Health in Chicago. Dr. Houlberg is also chair of the AMA’s Advisory Committee on


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Dr. Houlberg, we're going to start with you. The question, are people who are HIV positive at increased risk for severe complications from COVID-19? Let's talk about that.

**Dr. Houlberg:** So from what we understand, people who are receiving treatment for HIV and have well-controlled HIV do not have increased risk for complications from COVID-19. What we do know is that people living with HIV have more comorbidities, which are associated with worse outcomes with COVID-19, such as diabetes, high blood pressure, heart issues and kidney issues. So in that respect, certainly older adults with HIV are in a risk category if they have those comorbidities.

**Unger:** Mr. Gross, does the risk increase then when we begin to talk about an older population with HIV and what do we need to know about issues with aging and HIV and COVID?

**Gross:** Sure. Well, I'll speak just specific to HIV and aging first. We know that HIV disproportionately impacts older adults. About 65% of people living with HIV in the United States right now are over the age of 50, and this percentage actually increases when you're in major metropolitan areas. I can speak more anecdotally, I'm not a medical expert, but I can speak to our clients at Sage that from day one of COVID, they were concerned about the impact it would have on whether they would be more susceptible to it.

**Unger:** Ms. Dispenza, anything to add there?

**Dispenza:** I think that the social service aspect of the COVID epidemic has been really important to not only connect people to medical care, but to each other, helping them find new ways that might be scary to connect together.

**Unger:** Dr. Houlberg, what does the data tell us about risk with the combination of age and HIV?

**Dr. Houlberg:** Well, because we think that people living with HIV who are older potentially develop diabetes earlier in life and have potentially more risk of developing diabetes. That confers a risk, so it's more that it's cumulative. So for younger adults who are living with HIV and it's well controlled, likely their risk is identical to a young adult who is HIV negative. But once you start the aging process, you get more and more medical complexity that plays a role, I think, in vulnerability with COVID-19.

**Unger:** I imagine that the importance of preventive care is even greater, at least in this period. We know that, that's something that people have been kind of passing on during the pandemic. Can you speak to that?
Dr. Houlberg: Absolutely. We do see that people living with HIV have been deferring their HIV visits, either because telemedicine is somewhat new. For some patients living with HIV, telemedicine is wonderful and they really enjoyed having actually increased access to a medical provider via telemedicine. But for many of our patients, they may postpone visits, postpone refills for medications, and then that can have an adverse action after a while.

Unger: Ms. Dispenza, can you talk about some of the social determinants of health that affect people who are aging with HIV and how COVID-19 has had an impact on that?

Dispenza: Housing has definitely been a challenge for our population, low-income housing, supportive housing, where people often don't need just a place to live, but they need the help that goes with it. And food insecurity has been huge, we've been very lucky in our community in Chicago that LGBTQ seniors have not been forgotten and tons of volunteers who bring food, who take food to people, who call friends. It's been incredibly moving, and COVID has shown the weaknesses, but also the strengths of society, and the LGBTQ community especially has really stepped up in an incredibly moving way.

Gross: Yeah. I'd love to add to that because I think it's so important to look at where the gaps in care lie, but also my experience, along with Jill, it sounds like is that there has been a great deal of resiliency displayed among our folks who are living with HIV, older adults. Some of them actually, during this period, SAGE is offering up to a hundred pieces of remote programming a week, and so for those who can access it via their computer or telephonically, I have some clients who are going to three or four or five yoga classes and language classes and support groups a day, and so there is a diversity of experience in that.

Dispenza: And what we have seen at the center, we have town hall apartments, which is low-income senior housing and folks there who live there have been saying, "This is not my first epidemic," and so they have a calmness and a view of a longer-term we can get through this that maybe younger people don't. So it's been a wonderful thing to hear from that community that we can help you through this because we've been through this.

Gross: That's been our experience as well, yeah.

Unger: So some of those activities you address the social aspects of this. Can you talk a little bit more about issues around stigma and discrimination that accompany this?

Dispenza: Stigma is huge for HIV folks. There's a perception in the LGBTQ community that there's a stigma against getting older. What we have seen is when older people in our community need help, they get it from younger people, so I think some of that is internalized stigma from the outside. But that helps people feel connected. It helps them become adherent. We have a Chicagoland HIV resource hub that we house with the AIDS Foundation. People can call, they can walk in, we can meet with
them. We've hooked up hundreds and hundreds of seniors living with HIV who are vulnerable to food, to housing, to medicine, to population-centered health homes. And they can call us, they can walk over, they can text us. They can access us any way. There's no wrong door. Any way that they access us, we can help them.

**Gross:** I'm sorry. Go ahead.

**Unger:** No, please go ahead, Mr. Gross.

**Gross:** I was just going to say that I think one of the most comprehensive studies of HIV in older adults, the ROAH study just rolled out its second iteration and really did find these things that we knew already, increased levels of stigma, isolation, depression, loneliness, and to SAGE, it sounds like our agencies are doing similar things in terms of trying to connect people virtually during this time, to find all the opportunities.

**Unger:** I mean, clearly those issues are going to have a big impact on mental health. Dr. Houlberg, what are you seeing in that regard?

**Dr. Houlberg:** Sure. We've seen an increase dramatically in depression and anxiety, and in some cases people living with serious and persistent mental illness having decompensation during this time, so I think it's had a very difficult worsening of what was already kind of a challenging mental health situation, certainly within our ... The accessibility of mental health services is very low, so it's a very precious resource that is not plentifully available. In some cases, the telemedicine and teletherapy and tele-psychiatry has been a huge tool in addressing this. In other ways, I do think it's a function of loneliness, which is a huge aging issue, so as much as people don't necessarily understand, it's an aging issue, but it's also a societal issue, so I think loneliness really has significant health outcomes from it. Young people have experienced this as well, meaning in a lot of different ways, but I think it is particularly profound for older adults. And we do see this in geriatrics, that it is a major predictor of adverse outcomes and can certainly a part of that is mental health as a part of wellness.

**Gross:** One of the things that we've seen at the center is our whole existence for seniors is -- don't be isolated, come in, come in and spend time together, be with each other. And literally this epidemic made us go away from each other. Don't talk to each other straight away, stay away, stay safe. And so having to create things where they could access and still get that same feeling of community is a challenge, so that we want them to be safe and we want them to also speak to each other. So we have friendly visitors who will call weekly, and we have situations where we're checking in. We have unemployment program for seniors, a federal program that brings them into the center to help us and help each other. So we do what we can well while trying very hard to keep them safe. They were delayed coming back into the center where the rest of the staff came in because we wanted to make sure we were safe enough for the seniors coming in.
Dr. Houlberg: So just to build on that, we, in providing HIV care and people who have had been living with HIV for many, many years, when they are first diagnosed, a lot of times, they're experiencing a lot of stigma, including health care providers, not wanting to touch them, not wanting to shake their hand, keeping a distance once they learn their HIV status. There still is a strong stigma that we see and that patients report. If they're seeking many different services, once their HIV status is known that people stand further away from them. And so it's actually a really important part of HIV treatment and care to have physical contact with patients, meaning to be very close to them, to shake their hand, to make eye contact, to not be afraid of doing a physical exam. And so those are things that people feel, I think, in the exam room, they feel that. So of course the COVID situation has made this very difficult because a lot of people who've experienced this kind of stigma are, everyone's afraid of everyone right now. So it's very, it makes it very, very challenging from a stigma perspective to kind of cross those barriers because we want to keep people safe. But at the same time, a lot of the things that we utilize to engage patients, can't be utilized the way.

Unger: Dr. Houlberg, that actually brings up the point that so many of the things that were wrong before the pandemic are now just exacerbated by it. As a physician, what would you want to tell other physicians that they need to know about these issues in caring for this population during the pandemic?

Dr. Houlberg: I think that for older adults who are living with HIV, this is their second pandemic so they really have seen a massive changes in their group of friends and contacts, a massive loss of life in some cases, living through the HIV pandemic, which we're still in. So I think that having sensitivity to that experience in the context of today, I think is really important and the idea of what it means to feel contagious or what it means to feel like people are afraid of you. So I think those are things just to name for patients and having awareness that, that might be bringing up a lot of things for them from the past.

Gross: I would also say that for us, I know that our transgender elders continue to face even higher risks during this time with a medical system that often is ill prepare to serve their needs in a competent way. One national program that SAGE has is SAGE Care, which provides training to health care providers and other groups around these issues. And they actually have a specific track around HIV and aging that could be really helpful.

Unger: Is insurance coverage a significant and growing issue for the people that you see? Mr. Gross?

Gross: It can be. Yes. I mean, we are, New York state, we're lucky to have some avenues there that are harder than other states.

Unger: So let's talk about what kind of advocacy and policy issues need to be elevated right now to support this population. Ms. Dispenza, will you start?
Dispenza: Our senior program has a Senior Voice program, which brings our elders together and they go to government meetings, to politicians. They educate businesses and communities about who they are; they're not scary and that they are living with HIV and they've lived with it for a very long time. We run the State of Illinois' HIV STD hotline, and there's still a lot of people who call and think if you get HIV, you die. Unfortunately in some cases that can happen, but because people are not accessing treatment, but to see an older a person who is living a full, beautiful life with HIV, sometimes it's surprising for folks. So their advocacy is about educating who they are and how they could contribute to the world.

Unger: Mr. Gross, from in terms of advocacy and policy issues?

Gross: Yeah. Sage has a national advocacy program, and I would say two things from that that we've been in championing the inclusion of older people with HIV as a target population under the Older Americans Act, OAA, which funds programs across the country like Meals on Wheels program. We also actually worked in Illinois with Quality Illinois and other advocates on the ground to enact the very first law in the nation designating older people with HIV as our greatest social needs population or target population in the state. And we're working on similar legislation in DC now, and hope to roll it out in other states as well.

Unger: Dr. Houlberg?

Dr. Houlberg: I think that having access to health care is still very challenging for many older adults. So although many are eligible for Medicare, their out of pocket costs are a real limitation. So medications cost money, health care costs money for out of pocket. And many older adults have a very narrow range of expenses that they can absorb past what they've planned. So I see the economic effects of this and really the social determinants effects as needing policy solutions. So I think we need to have a much stronger network of social services and basic needs.

So most of this to me, housing is like the most dire need that we see, I think, in terms of social determinants of health, because we can't really help or support people's health unless they're housed effectively because everything else sort of takes a second place to that survival. So I think until our society can kind of prioritize those things from a policy and equity standpoint, that to me, is the first step. People want to have a high tech solution to this, so they want technology to come in and fix COVID and cure it. And really the reality is that some of these "low tech" solutions are the ones that we know work. And we could enact policy that would make this much more accessible for all of our older adults.

Dispenza: And as we've seen with the struggle in nursing homes with COVID that our seniors have struggled forever with acceptance when they move into a nursing home or assisted living. So it's very important to us that we continue to advocate and teach nursing home staff and assisted living staff about the people that they're serving, if they are living with HIV, if they're LGBTQ. The last thing that
senior needs to do is go back into the closet when they're so vulnerable and so that's one of our big advocacy subjects.

**Unger:** Lastly, there is a concern that this population has been largely unseen. So what does that mean to you and what is the most critical thing to help aging people with HIV achieve optimal health during and beyond COVID, Mr. Gross?

**Gross:** I love your question. SAGE’s tagline is, we refuse to be invisible. And for the very reasons you're talking about very often, although these populations are resilient, they have specific needs that aren't always met. And in my anecdotal experience with them, they don't always feel witnessed. Many of our folks at SAGE lost most of their peer group over the decades from HIV, AIDS and other illnesses. And I think it's so important to provide a sense of witnessing for them. One solution we have of that, aside of our regular programming, we have friendly visitor programs as well, that can really create some wonderful social connections for our older adults or older adults living with HIV cross-generationally. So they're seeing their witness both in their lives, 40, 50, 60 years ago, as well as what's going in their life right now.

**Unger:** Well, thank you so much, Mr. Gross, Dr. Houlberg, Ms. Dispenza, for being with here, being with us here today and sharing your perspectives. That's it for today’s COVID-19 Update. We'll be back with another segment soon. For updated resources on COVID-19 visit ama-assn.org/covid-19. Thanks for joining us and please take care.

**Disclaimer:** The viewpoints expressed in this video are those of the participants and/or do not necessarily reflect the views and policies of the AMA.

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**988 Suicide & Crisis Lifeline**

With an increased number of people reporting worsening mental health in recent years, it is imperative that people are aware of the 988 Suicide & Crisis Lifeline (formerly known as the National Suicide Prevention Lifeline) telephone program.

People experiencing a suicidal, substance use, and/or mental health crisis, or any other kind of emotional distress can call, chat or text 988, and speak to trained crisis counselors. The national hotline is available 24 hours a day, 7 days a week.

The previous National Suicide Prevention Lifeline phone number (1-800-273-8255) will continue to be operational and route calls to 988 indefinitely.