



CONNECTING CARE PODCAST // EPISODE #2 // TRANSCRIPTS

HIV Services for People Who Inject Drugs

Alex Walley

When people learn there's a pill that's been available for many years, that will keep them safe from HIV. They are surprised and may want to know more.

When people are surprised and even upset, we know we need to do more. You're listening to Connecting Care, a podcast of the HRSA funded initiative, strengthening systems of care for people with HIV and opioid use disorder. We are working to ensure that people with HIV and OUD have access to care, treatment, and recovery services that are coordinated, client centered, and culturally responsive. I'm Alex Walley, I'm an HIV primary care doctor and addiction medicine specialist in Boston, Massachusetts.

This is the first of a two-part series, HIV pre-exposure prophylaxis among people who inject drugs. Today, we'll discuss initiating PrEP. I'm joined by my colleagues, Dr. Jessica Taylor, who you just heard from and Dr. Sim Kimmel.

Jessica Taylor

I'm Jessica Taylor, I'm an HIV primary care doctor and addiction specialist. And I'm the medical director of our bridge clinic at Boston Medical Center.

Sim Kimmel

I'm Sim Kimmel, I'm an HIV primary care provider and addiction and infectious disease specialist, and the medical director for addiction services at an HIV prevention, harm reduction program at Boston Medical Center.

Alex Walley

So, Jess and Sim, I'm really excited about today's topic, which is going to be pre-exposure prophylaxis and initiating it and people who inject drugs. And I'm particularly excited about it now, because I just had this recent experience where I was working in the inpatient hospital at Boston Medical Center on the addiction consult service. And each time I worked there, there's something different that I notice, and this time it was the number of patients and the number of providers who were thinking about pre-exposure prophylaxis. And to be honest, I've been thinking about PrEP as a way to reduce the risk of HIV for several years, and I've been trying to talk to my patients and I've talked to some of my colleagues. I frankly found it exhausting because it just didn't seem to be getting anywhere. And I know we have a long way to go with PrEP and people who inject drugs, but I did feel this time around this year, that for the first time we're actually getting somewhere. And so that's why I'm excited to talk about this topic today. How about you guys?

Sim Kimmel

I'm excited about this topic also because I've also noticed such a change. People are hearing about PrEP; patients are hearing about PrEP in multiple places. They're hearing about it in their primary care doctor's offices, in the HIV clinic, in the addiction treatment programs. They're hearing about it from their harm reduction programs. They're hearing about it in places that take care of people who are experiencing homelessness. I've also noticed a big change, and I think people are nervous because there's been a local outbreak of HIV among people who are using drugs. And I think people are really wanting to protect themselves and even more than protect themselves, they want to protect each other and protect their communities.

Jessica Taylor

I agree. I'm also really thrilled that we're sitting down to talk about this today and think this is really the right time. For one thing I think there is more community and provider awareness than we've ever seen before, just like what's being said. But I also think that as providers we're really concerned by the surging HIV infections and the outbreaks that we've been seeing before the pandemic, but also during the pandemic. And we've been very concerned as our patients have about a surge in new HIV infections related to disruption and services during the COVID-19 pandemic. And I can say that certainly played out in my program and at our institution where the number of new HIV infections related to injection drug use in 2020 was much higher than what we'd seen in prior years, actually almost three and a half times as high as what we'd seen in the past.

So, we know that locally, we're seeing very high transmission. We know that Boston is not alone and that places across the country are seeing HIV outbreaks among people who inject drugs and actually internationally as well. So, this is really a timely topic, and one that I love to be a part of, because I think on the other side, being a receiving clinician and HIV specialist, seeing someone with a new diagnosis, it can be really challenging to see someone for the first time, look at their chart and realize how many opportunities were missed to connect to that patient and offer really high-quality evidence-based HIV prevention services, including PrEP. So, thank you for being here and for the opportunity to do this.

Alex Walley

Great. So, I want to get into the case. This is such a big topic that we decided to split it into two parts, and I'm not going to give everything away, but today we're going to hear about a case that has gone well and really focus on the issues of initiating PrEP. And then next time on our next episode, we're going to talk about a case where things didn't go so well and really think about the challenges of continuing people on PrEP after they're started. So, Jess, I want to invite you to tell us about this case and Sim and I, we'll sit back and hear how it went.

Jessica Taylor

Sure. So, I'm going to share about a case of a patient that I've worked with very closely for a couple of years, who I initially met about four years ago, and she is a woman fairly close in age to me who has a history of severe opioid and stimulant use disorders and has been involved in transactional sex for about 15 years or so. And so, I met her in our bridge clinic, which is our low-barrier program, that's meant to really rapidly connect people with substance use disorders, to medications, for opioid use disorder and other treatment. She came in wanting to talk about starting buprenorphine. And at that first visit, it stood out to me that she was at fairly high risk for acquiring HIV infection because of shared injection equipment and also because of sex work. And she described to me, not typically using condoms for vaginal and oral sex in large part, because she's paid more if she does not use condoms.

So, for those two reasons, both the injection related and sexual risk, I thought that it would be a good opportunity to really focus on HIV prevention and talk about different ways to reduce the risk of HIV

infections, including HIV pre-exposure prophylaxis or PrEP. And so, we were sitting in the visit, I brought up screening for infections and talked about different strategies to prevent HIV, including PrEP. And I just remember her face falling, and we were sitting in our bridge clinic, which as Alex and Sim know is a fairly small space for, you're sitting pretty close to the patient and I can just still see her face when I mentioned PrEP, then explained there's a pill that you can take once a day to decrease your chances of getting HIV infection.

And she was angry and she said, "What do you mean there's a pill for this? How long has it been out?" And I said, it has had a CDC recommendation since 2013, we talked through that. And she said, "You mean that I could have been on something to prevent HIV all this time and no one ever told me about it." And she was really, really understandably, very upset that the concern about getting HIV has really weighed on her over the years and thinking through how to prevent HIV and reduce her risk has been something that really has been concerning to her. And here as a medical system, we've had an option available that we'll talk about more today, but it hadn't been offered to her and hadn't been provided to her in a way that she could access.

Alex Walley

Jess, I want to stop you there actually and see if between Sim and I, we have any clarifying questions. The patient that you're describing is somebody who's coming in, looking for treatment for their substance use disorder to a low-barrier access treatment program or treatment clinic, and you get into a discussion about HIV risk. And so, my first question is you said that she's involved in transactional sex and she did sex work, but what language do you actually use with the patient when you're talking about transactional sex or sex work?

Jessica Taylor

Yeah, I would say in situations like this or talking about any topic that can be sensitive or any behaviors that society may stigmatize at large, I think taking cues from the patient is really the most important piece. Sometimes that means listening to and echoing the language that our patients use. So, in this particular case, I was talking to my patient about her substance use and how much she used and was asking how much heroin she was using per day, how much cocaine at the time she was using per day and how much she was spending. And she disclosed that she was supporting her substance use by doing dates. That in the Boston area is language that's very commonly used to describe sex work, doing dates is pretty commonly understood as formal sex work or transactional sex.

But I didn't know that when I first started doing this work. And so, I had to ask and say, "When you say doing dates, what do you mean?" And patients might use other language to describe sex work, as a clinician if I'm trying to ask, I often just say very directly, do you ever trade sex for drugs, money, a place to stay or something else? And I like to be very concrete, "Do you ever trade sex for something else?" Because many people who are involved in transactional sex may not identify as doing sex work. So, for example, a lot of our younger patients might be offered a couch to stay on or a place to crash and be expected to provide sex in exchange for staying in that apartment or that place, and not view that as sex work. But still if I as the provider am hoping to discuss HIV prevention and help the patient accurately assess their HIV risk, that's important information for me to understand if they're willing to share with me.

I think too, it's always important to use caution when we screen for stigmatized behaviors or things that can be difficult for patients to disclose and make sure we share why we're asking. So, I don't just ask about sex work or sexual risk because I'm curious, or I want the information, I really share with my patients that the reason I ask these questions, I know they're really personal. In many cases, I've just met someone and I'm asking about their sexual practices, about sharing needles, things that are really hard

to disclose. So, I'd like to explain, I'm asking because this information will help me know what to offer in terms of ways to keep yourself safe, ways to decrease your chances of HIV or other infections, avoid overdose and other cases. So, I think it's important to lead with why we're asking and also normalize the questions.

Alex Walley

Well, in a discussion about PrEP, these issues are particularly important because they're part of the eligibility criteria for it. I'm not sure we actually have defined what PrEP is yet. So, could you do that for us, Jess?

Jessica Taylor

When we're talking about PrEP today, we're talking about HIV pre-exposure prophylaxis. And what we generally mean when we talk about PrEP is using daily tenofovir disoproxil fumarate and emtricitabine, so essentially taking two medications that are in a combination pill once a day, to decrease the chances of getting HIV and someone who's at risk of acquiring HIV because of either injection related or sexual exposures. So, we'll say PrEP, and we'll use that to mean taking a daily pill to prevent HIV.

Alex Walley

Great. Thanks. Sim, do you have any clarifying questions you have for Jess about the case so far?

Sim Kimmel

I think one thing that Jess really highlighted that's super important is the idea of asking people specifically about behaviors as opposed to identities or as opposed to occupations. And that's a lesson from the earlier days of the HIV epidemic as well, that the idea of identifying as gay is not the same thing as actually men who are having sex with men, which is really the risk behavior. And so, I think it's a similar point that Jess so carefully and thoughtfully articulated when we're talking about transactional sex or sex work, that somebody may not think of themselves really as a sex worker or as a more stigmatized term that defines that, but we really need to be drilling down on those behaviors so that then we can figure out what to offer people, so just wanted to add that.

Alex Walley

Great, any reflections on the case at this point beyond what you just mentioned, Sim?

Sim Kimmel

Jess mentioned that this patient had multiple encounters with the healthcare system before. Can you talk a little about what those encounters were like? Were they in the emergency department? Had she sought addiction care before? Did she have a primary care doctor?

Jessica Taylor

Sure. So, at the time she did not have a primary care doctor. She had had multiple admissions leading up to meeting us in our bridge clinic. And she'd had several overdoses, but was not connected to a primary care provider. And I think it would be fair to say wasn't connected to a consistent care location, even outside of what we typically think of as a primary care setting.

Alex Walley

So, I think Sim you're getting to the point that I wanted to highlight, and I think was one of Jess's main features of this case is the surprise that this person had. And really the shock that no one had talked to her about it earlier, because when I've talked to patients about PrEP in the last many years, they look at me often like, what is that? I've never heard of that. Does that even make sense? And that's really what has changed for me. Usually I'm in the clinic, I'm taking care of patients who already had HIV. And so, I ended up talking to them about PrEP, and when I'm thinking about their partners, their sexual partners who are HIV negative, but when I'm on the consult service and the general hospital, that's when I get to see patients who don't have HIV and, in the past, they always didn't know about PrEP and it was really starting from scratch.

And what has changed this time around was for the first time there were actually patients and then also providers who are knowledgeable about it, which I think gets to your point about where did they hear about it? Or where did they not hear about it? And so, at this point in our hospital, they are hearing about it when they're admitted to the hospital on a regular basis, some are hearing about it in the emergency department, some are hearing about it in primary care, and some are hearing about it through their syringe service program or their harm reduction program. So, let's get back to the case, Jess take us from this moment where she expressed surprise.

Jessica Taylor

Sure. And if it's okay, I'll just add to what you said about barriers to PrEP, which is that if you read PrEP literature, particularly around people who inject drugs and uptake, you'll see a lot of attribution of low uptake to low PrEP knowledge and low patient knowledge about PrEP. And I think anytime we hear that, we need to say, well, why is that? And that's actually a medical system side barrier, as a medical system, we have not historically done a good enough job or any job teaching our patients about this option for HIV prevention and making it available in a way that is accessible and that the patients want to engage with. So, I think any time I hear that knowledge, knowledge coming into the conversation as an issue, I'm always just reflecting on how that reflects our shortcomings as a medical system.

Alex Walley

So, we often will say that to blame the patient, right? But what you're saying is we really need to blame ourselves in the system.

Jessica Taylor

Exactly. Very well said. So back in the room with my patient who I was meeting for the first time, we talked about PrEP and I explained that it's a pill that people can choose to take once a day to prevent HIV. That it is incredibly effective if taken every day at reducing HIV from both sexual and injection related exposures. That we think in cis-gender women, like my patient, that adherence needs to be really very, very high and for it to have the best effect. So really taking it every single day. We talked about pros and cons of taking it in terms of potential side effects. We talked about what can happen if people are not able to take it every day as planned and what those downsides can be, which that part of the conversation taps into I think a lot of provider fears about using PrEP in people who inject drugs or in any population with adherence barriers.

And I think we'll delve into those in a little more detail in a few minutes. And then we talked about what monitoring is required to start and continue PrEP. And so, we agreed that we would do labs that first day and then that we would see each other regularly to make sure that the pros still outweigh the cons, that she still wanted to continue PrEP, that she still had risk factors that made it worthwhile to be on PrEP.

Alex Walley

So, Jess, you just, I think gave us a lot of great information about how to talk to people about PrEP. Can you clarify what indications this patient had for PrEP and then put that in the context of, in general, when is PrEP indicated?

Jessica Taylor

Sure. So, as we were talking about earlier, we talked about risk factors for HIV and behaviors that can increase risk. And so, I like to ask people how long ago was the last time that you shared a needle or that you used a needle that was used by someone else and went second? And so, I asked my patient and her most recent receptive syringe sharing or needle sharing had been the morning of the visit. And I also asked about most recent condomless sex. Condomless is a word that I think has made its way into the research vernacular. So, with the patient, sometimes I say sex without a condom and her most recent episode of vaginal receptive condomless sex had been, I can't remember specifically, but a few days prior, approximately, and we also talked about her partners and what the HIV risk of her partners was.

And some of her clients were people who inject drugs, including cis-gender men who inject drugs. And some of her clients were of unknown HIV status. And she found herself often in situations where it wasn't possible to ask about HIV status or to always negotiate condom use. And so, with those two factors, she met several criteria for a PrEP discussion, according to the CDC. When we look at our guidelines, we generally think about looking at past six-month risk and among people who inject drugs, we should be talking about PrEP, if someone has shared a needle in the last six months. So, if someone is a person who injects drugs does not currently have HIV infection and they've shared a needle in the last six months, or if they have sexual risk, and what does that mean? So, by sexual risk, we mean in the last six months, condomless sex with a partner who is at high risk of HIV infection.

And that can include a partner who injects drugs. It can include partners of unknown HIV status who are potentially at risk. It can also include partners, who are people living with HIV. I say that with the caveat that if someone is living with HIV and takes HIV treatment, antiretroviral therapy every day as prescribed and maintains an undetectable HIV viral load, it's not possible to transmit HIV sexually in those cases. So, I say that with that caveat, but generally speaking in the past six months, if someone has had a receptive syringe sharing episode or sex without a condom with someone at risk of HIV, we really need to be zeroing in on what their risk is right now and thinking about offering PrEP. And last thing that I'll say is that we have a few other proxies for sexual risk. So, we think about bacterial sexually transmitted infections, specifically gonorrhea and syphilis, but also chlamydia and men who have sex with men as being potentially risk factors for acquiring HIV. That should prompt us to have a discussion about HIV prevention that includes pre-exposure prophylaxis.

Alex Walley

Are there any things that rule out PrEP? So, you just told us about the eligibility criteria, but are there things that we need to make sure if somebody doesn't have before we prescribe PrEP?

Jessica Taylor

Sure. First and foremost is HIV infection. So PrEP is an HIV prevention tool. And if someone has HIV infection, we would want to give them HIV treatment, which is typically a different set of medications. Typically, three though, sometimes two medications. But what's very clear is that the two medications that we use for PrEP are not enough to treat HIV once someone has infection. So, we got to make sure we know their HIV status. Second, we want to make sure we understand whether the person has hepatitis B. The reason for that is that the medicines we use for PrEP can also treat hepatitis B. And that doesn't mean that we can't do PrEP in someone with chronic hepatitis B, but it does mean that the conversation is a little bit different in terms of what the pros and cons will be of starting and stopping.

So, we always want to check a hepatitis B surface antigen at a minimum to understand someone's hepatitis B status before we move forward with PrEP.

Thirdly, we always want to understand someone's kidney function. So tenofovir disoproxil fumarate and emtricitabine, which is currently the only FDA approved option for PrEP in people who inject drugs, is a medicine that we can only use in people with normal kidney function. Last couple of things that I spend on the baseline tests, so when people who may become pregnant, I check a pregnancy test. And again, we use PrEP in people who are pregnant. So, it's not that you cannot use PrEP, but the conversation and the counseling become a little bit different if someone is pregnant. And then finally I take the opportunity to round out screening for bacterial sexually transmitted infections.

Alex Walley

Thanks for going through that. This patient seems like the ideal patient to consider pre-exposure prophylaxis. We'll get in, in a minute to exactly how you navigated it. But first I want Sim to talk to us about barriers to initiating PrEP, his thoughts on what keeps us from initiating prep in more patients.

Sim Kimmel

Thanks for asking that question. I think we've already heard some of this, that there's a knowledge gap. There's a knowledge gap for patients, and there's also a knowledge gap for providers. So, I think that's an important thing and there's a lot of reasons for that. Some of that actually probably has to do with the marketing of PrEP, specifically, not marketed towards people who use drugs. But then there's a lot of other barriers, even once you get to a patient who knows about PrEP and a provider who knows about PrEP. Jess mentioned that there's lab tests that are required to start these medications. So particularly wanting to know someone's HIV status and getting a blood draw for some patients can really be a big barrier. People may be scared of going to a phlebotomy site of actually going to a hospital site.

They may be worried about the way that they'll be looked at by the phlebotomist. They may be worried about actually having access because they've been injecting and their veins may be sclerotic and it may be more difficult to get blood. That's one immediate logistical barrier. There's another logistical barrier, which is once there's a prescription, how do you actually get the patient to go pick the prescription up and then continue to take the medication? And there's a lot of reasons why somebody might not be able to do all those things. They have to show up to the pharmacy. They have to have the right insurance to be able to pay for the medication, and then they need to be able to store the medication. And in a patient like this who may be experiencing homelessness, or maybe moving around a lot, maybe in multiple different living situations, it can be really hard to keep that medication to not lose that medication.

So lost and stolen medications is a big issue. I think one other issue that is worth talking about is stigma. And so, some people don't want to... In addition to the stigma around injection drug use, they may not want the stigma of being somebody who's at risk for HIV or somebody thinking that maybe they have HIV, if they actually see one of these medications on that person. So, I think those are barriers. Another barrier is, this patient, for instance, is seeking care, seeking addiction care so that she has a lot of high risk, or I should say behaviors that put her at risk for HIV acquisition, but she's also interested in reducing those risks. It sounds like she wants to get treated with buprenorphine. She'd likely is going to reduce her injections if she actually gets started on that treatment.

And so, people's perceptions of their risk and their ideas about what they want for themselves may change as they view starting addiction treatment, the chance to be somebody who's not injecting. And they want to view their future selves as someone who may not inject, even though we know that

substance use disorders are chronic relapsing diseases and she may return to injecting drug use at some point. So that perception of risk is a really big barrier.

And then I think there's also a problem with people need to access PrEP typically historically in PrEP specific clinics. So, we've talked about knowledge, but also the sites of care for people to get PrEPed. So, people in this situation, these patients entering into a low-barrier program, but it's still a clinical site. And so, people need to take on a certain kind of identity as a patient to be able to access those resources. So, people may not want to take that on, if we could deliver PrEP in a way where it's not quite so clinical, delivered by people who they know and trust as opposed to clinicians, where there's a lot of skepticism often. I think that's another barrier, that is something we're thinking about from assistance perspective.

Jessica Taylor

And can I ask a follow up question to something you said? You hit on something that comes up in our bridge clinic all the time, which is that we're seeing patients for an initial visit, they've overcome multiple barriers to get into our bridge clinic, which is based in a hospital. So as low-barrier as we try to be, you do still have to come through the main entrance of a hospital to see us. And we recommend buprenorphine, we're getting started. We might recommend PrEP and people say, I'm never going to inject again, or I'm never going to have sex again. I have actually had people make that statement in my clinic. So why would I need this medicine? And then sometimes the follow-up is, do you not believe me that I'm going to get into recovery? And so I'm curious if you have any suggestions for how to navigate that space of affirming all of the effort and motivation and positive steps forward, people are making an early recovery while still trying to talk about HIV prevention.

Sim Kimmel

That's a really good question and it's a really hard one. I like to affirm as much as I can the positive steps people are making, but then also talk about a plan B, the safety net, what will happen if things don't go as planned. And then also, I often help people think a bit about what's happened in the past, when they've entered into addiction treatment and what's happened to their behaviors and what's happened to their injection practices. And then what happened when they started injecting again in the past. And I think oftentimes that reflection on their own history can help them hold together their aspirations for addiction treatment, but also recognize the risk. But then I think it's a very tricky conversation and every individual is a little bit different.

Jessica Taylor

I was just thinking, you can tell that Alex trained both of us because I also learned plan A and plan B from Alex in terms of a language option in these discussions. And Alex, I think I say exactly what I heard you say one time, which is plan A, is that you start buprenorphine and you never inject again. Let's talk about having a plan B as a backup. I think the other strategy I've used, particularly with our young patients where relapsed planning can be really threatening to the early recovery period is to really focus on the CDC criteria being about the last six months. And of course, as the provider, I'm trying to look ahead to the next period of time and to future risk. But I think it can be helpful, I often say our guidelines say that, we should be offering this to you.

And it is the standard of care until it has been six months since the last exposure. And so fantastic, your last exposure was one week ago. You're one week down, great. And so we'll have this conversation again next month and we'll keep checking in, but to try to get any impression of doubt about the next phase of the recovery, just off the table and say, it doesn't even matter. We need to talk about this for me to be doing a good job because there's been risk in the last six months.

Alex Walley

Great. So, I want to hear more about, or what happened next. I think it's good to think about the barriers, but this is a person who got through those barriers and was there with Jess in the clinic. How did that conversation go and initiating PrEP, or did you initiate PrEP? What happened next with the patient?

Jessica Taylor

Well, I was clearly very excited to initiate PrEP and then I got more history as we talked about. And my patient shared that her last shared needle event had been the morning of the visit, very, very recently prior to the visit. And so that was really a sign that I needed to change gears and actually think about HIV post-exposure prophylaxis or PEP, you'll sometimes hear that called non-occupational post-exposure prophylaxis or PEP, when it's outside of say a healthcare worker hospital setting. And the reason for that is that my patient had, had an exposure within 72 hours of the visit. And our guidelines say that if that's the case, if someone has had a very recent high-risk risk exposure within 72 hours per the guidelines that we should use, post-exposure prophylaxis with three HIV medications instead of the two medications that we use for PrEP.

Alex Walley

So, this is the so-called PEP, and then to PrEP strategy. So, tell us more, as far as you instituted PEP with this patient, and then what happened and how did it go?

Jessica Taylor

Yeah, I think PEP is a really underappreciated and under recognized pathway to get people who might have frequent and high-risk exposures onto PrEP. And I say that because as a clinician that does PrEP in people who inject drugs and a primary care provider, it's scary when you're thinking about starting just tenofovir and emtricitabine and someone who has had a recent exposure. Because we worry about HIV resistance, if someone has an early HIV infection and especially in HIV infection that is within the window period of the test. So, what I mean by that is that the window period of any test, including any HIV test is the time between infection in this case and when the test is positive. So, for HIV, with the testing that we typically use, the window period is about 21 days, maybe a little bit shorter than that, but we know that for the first, say two to three weeks after an infection, we may not be able to test for HIV accurately.

And that as the provider that can leave you in a scary place, because the worry would be what if I've missed acute HIV? Not because I haven't thought about it, but because I do not have access to a test that is accurate right now because it's too early and I start just tenofovir disoproxil fumarate and emtricitabine, two drugs. And then my patient goes on to have HIV infection being partially treated with two drugs and develops an HIV virus that is resistant to these two medications, which turn out to form the backbone of most HIV treatment regimens. So, if someone has resistance to the two of them, their HIV treatment becomes much more complicated and just much more unpleasant, you get into more pills per day and more complexity. So, I think that fear has really on the provider side, been a limiting factor in willingness to prescribe PrEP because people are don't want to cause harm in that way.

If a patient remains HIV negative, we can immediately transition to PrEP with just the two drugs tenofovir and emtricitabine. And that's in a single pill. And so, patients have continuous protection, but without that initial angst of potentially missing an acute HIV infection. Post-exposure prophylaxis, if started within 72 hours can prevent HIV infection. So, if someone's been exposed, it can prevent the infection, but even in the event of not preventing an infection, if you've missed it and someone has acute HIV, at least you're starting adequate treatment. And so, you're not putting the patient at risk necessarily of developing resistance.

Alex Walley

So, I want to reiterate a couple points that comes up in this explanation. So, one of the eligibility criteria for PrEP is a negative HIV test, and you can't get a reliable, negative HIV test in somebody who has had recent exposure. The patient presented here has had exposure potentially that day. So very recent and then also has multiple exposures, not just injection exposures, but also sex exposures. And so, this is exactly the right person to be on PrEP, a very high-risk person, but they're prevented from starting PrEP because we can't get a reliable HIV test. And so the way out of that conundrum is to start them on PEP. And it turns out that PEP from a patient perspective is actually quite similar experience to PrEP. It's just three drugs instead of two drugs and a difference in the way the monitoring is conducted as far as the type of testing. But if all goes well, the person can be converted to PrEP after one month. So, tell us what happened, is that what happened?

Jessica Taylor

That was what I hoped would happen. And so that day we started buprenorphine, we talked about residential treatment and she wasn't ready for residential treatment or interested in making a change at that point. We talked about a few other active health conditions and we started post-exposure prophylaxis, three drugs. I chose to use a combination pill, so effectively, she was still taking one tablet once a day for post-exposure prophylaxis. And we made a plan to do repeat HIV tests and then transition immediately to PrEP at the end of 28 days. We had a few hiccups and if you missed visits and a few times that we tried to reach each other, and the next time that I saw the patient, if I remember the sequence correctly, she had stopped PEP. And we ultimately over the next probably two years did two to three more PEP courses and then did transition her to pre-exposure prophylaxis PrEP.

And I would say over the last couple of years, she's had periods of up to four to six months on PrEP consistently and is still HIV negative. And so, I think reflecting on this case, it may have not been the PEP to PrEP course that I would want to write a textbook about or that the guidelines necessarily lay out for us. But I think the reality of working with patients that face really substantial structural barriers, and Sim mentioned homelessness a minute ago, that has certainly been a factor for this patient. Insurance barriers, transportation barriers, real concrete challenges to accessing and staying in care reliably, access to a telephone. It's sometimes looks a little different than what the guidelines say and what the textbook says. But I think with having low-barrier access, with being able to welcome her back, whenever she's ready to come back to care, we've been able to re-evaluate and restart post-exposure prophylaxis or in some cases, PrEP, if there has not been high risk and keep her on it for reasonable stretches over the last couple of years with the outcome that today she remains HIV negative.

Alex Walley

All right. So, after hearing this case, Sim are you convinced? It seems complicated. Why should we go through all this hassle of doing PEP and PrEP? Shouldn't we just tell people to use condoms and inject with new and safe clean injection equipment.

Sim Kimmel

It does seem a little complicated, but it's not actually that complicated. It's really in some ways simpler than a lot of other interventions that clinicians are providing for patients and it's extremely effective. And so I think PrEP really needs to be part of any HIV prevention package that we delivered to patients. We've talked about some of the other strategies as well, condoms. We know that access to medications for opioid use disorder, frequent HIV testing, syringe service programs, condom distribution, safe injection facilities, and although they're not legal here, that all of these things also reduce HIV infections, but PrEP absolutely should be an important part of what we do for patients.

Alex Walley

So, we really dug in deep on this case and walked through it carefully. And I think we've provided a lot of great information on the efficacy barriers to really make progress. We need to implement; we need to enhance and expand access to PrEP and use of PrEP within a health system and within communities. I'd like to ask you guys to give your thoughts on how the health system can expand access to PrEP.

Sim Kimmel

I think we know that there needs to be knowledge. We need to provide more training both for patients and providers, but that's not just enough. There's going to have to be new systems developed. So there needs to be a specific PrEP teams, the way that there's addiction consult services to deliver these new interventions or deliver old interventions in a new setting. Sometimes there needs to be that support to foster these changes and to make sure that people have access to these services in new settings because existing systems don't have that capacity. So, making sure that there's that additional support, making sure that that PrEP information and access is available at places where people who are using drugs are already spending time, even if it's outside of the healthcare system. And that really requires investment from the Department of Public Health, from health departments to create those linkages and connections. And that's one of the big barriers. We know that these non-biomedical interventions are effective, but we need to pair them with these other biomedical interventions, with PrEP to make sure that people have access to these medications.

Alex Walley

I personally think that part of this sea change that I noticed when I was on the consult service, it is about patients learning more about PrEP. It's about healthcare providers learning more about PrEP, but it's also about the system of care providers and harm reduction services, knowing about PrEP and promoting PrEP. And that really has been facilitated through their support from the health department, both the city and the state health department. It's one thing to hear about a prevention intervention from your provider. It's really reinforced as we're seeing now with the move to vaccinate people for COVID, it really takes more than that. It takes a cultural change, a systematic change, systematic education from multiple touchpoints. Jess, anything you'd like to add on that?

Jessica Taylor

I think all of that is absolutely right. Thinking through payment reform that supports this is really important. So, a lot of the wraparound services that we've named patient navigation, outreach work, harm reduction, specialist access. These are all services that are not traditionally reimbursable in a traditional clinical medical model. And that is a major barrier because a lot of programs that are rolling out services like PEP and PrEP for people who inject drugs and nontraditional clinical spaces like, harm reduction programs, syringe service programs are really reliant on grant funding. And we're so fortunate in Massachusetts to have an incredibly supportive Department of Public Health, but grant funding is not universally accessible to programs across the country.

We know furthermore that many people who inject drugs live in areas of the country that are really in deserts as it relates to harm reduction services at all, and programs that offer this type of support. So, I think at the state level, at the federal level, thinking about how to ensure sustainability of patient navigation, of peer support, peer recovery coaching, and those types of services as a compliment to traditional clinical services is incredibly important.

Alex Walley

Okay. I think we have covered the landscape when it comes to initiating PrEP and people who inject drugs. I'm really looking forward to our next podcast where we're going to focus on bolstering adherence among people who are on PrEP. So, Jess, why does this matter? What's the big deal?

Jessica Taylor

Yeah. So, I think the reason that we all feel very strongly that addiction teams and general medicine teams should really take this on, is that the incidents of HIV or the lifetime risk of HIV in people who inject drugs is really staggeringly high. And so what I mean by that is that in the U.S. unless we start doing things much differently, one in 42 men who inject drugs is expected to contract HIV in his lifetime, that stat is one in 26 among women who inject drugs. And we just see huge staggering disparities based on race and ethnicity. So, we know for example, that one in seven black women who inject drugs will be expected to contract HIV in her lifetime. And we, I think could and should do an entire podcast on why that is and what the contributing factors are. But I say that to make the point that HIV incidence in people who inject drugs remains incredibly high in the United States in spite of an overall downtrend since the height of the epidemic, HIV is very prevalent with the outbreaks that we mentioned earlier.

We're just seeing really rapid increases in new infections in this population. And I'm personally nervous that we are only seeing the tip of the iceberg of new infections with all the barriers that the pandemic has created to testing, to treatment entry and to accessing harm reduction services. So, I'll just say that as a population, as a whole risk is incredibly high, that's why we're having this conversation. But if we don't really dig into this, we risk allowing disparities to continue and potentially worsen. And so, this is our lane as addiction teams, and it's time for us to get activated and take it on.

Alex Walley

Well said. I'm really glad you brought that up. And I do think that that is an important case for why we need to really focus on this. And while initiating PrEP among people who inject drugs has been a daunting problem and task, I do feel like we are making progress and that we're going to see ongoing progress. Unfortunately, I think part of that progress will be fueled by a new surge in HIV that at least we're feeling locally, and I think there are being seen in other communities. So, this is really as relevant as ever and so more to come. Jess part of both the PrEP and the PEP protocols are to test people for HIV. Do you have any thoughts on delivering HIV diagnosis, a positive result in this day and age?

Jessica Taylor

Sure. So, I think one of the reasons I'm so glad that we're talking about this today is that over the last year, at least at our institution where we have seen a dramatic rise in new HIV infections, specifically among people with an injection risk factor. What I've seen is that a lot of my colleagues who have never had to sit down with someone and share a new positive HIV diagnosis, a new positive test result, I should say, have had to do it for the first time. And as any HIV provider, I had the opportunity during my training to really practice how to disclose the diagnosis, to learn about best practices, to do it with a standardized patient, in my case, an actor and a preceptor giving me real-time feedback. That's something that really, with the change and the pandemic over the years really has not been a part of everyone's medical training.

And so many of our colleagues have had to share a new diagnosis, never having done it before, even though they're really launched into their career at this point. And so, for me, you just reflecting on the angst and worry that that is newly bringing up again in this generation of providers is another call to action to really use this moment to activate our providers, to get that HIV prevention piece in upfront, so that we're not having to sit down with patients and disclose a preventable diagnosis.

Alex Walley

Great. I'm glad you mentioned that. I was trained at a time when disclosing HIV diagnosis were quite common. And then we went through a period where it was less and less common, at least in the places where I was taking care of patients and the people who were injecting drugs that I was working with actually became much more concerned and interested in hepatitis C for example, and getting a hepatitis C diagnosis, which is also an important thing to learn how to deliver that message to patients. But it's a different story because hepatitis C is at this stage a quite curable condition, whereas HIV is not, it's a chronic treatable condition, but not curable. That is still despite years and years of effort is still quite stigmatized. So, the stakes are different with HIV than in hepatitis C. I think particularly in the group of people who inject drugs, we're seeing a surge in infections, and it's important for us to understand how to deliver that diagnosis.

And then in a way that's going to de-stigmatize people and engage them in care.

You're listening to Connecting Care. Our program was produced today by John Snow, Inc and Boston Medical Center. Connecting Care is supported by the HRSA funded project, Strengthening Systems of Care for People with HIV and Opioid Use Disorder. The project aims to enhance system level coordination and networks of care among Ryan White HIV/AIDS program recipients and other federal state, and local entities. You can learn more about the project and find resources at www.ssc.jsi.com. I'm Alex Walley, join us for part two of our discussion about PrEP for people who inject drugs. We'll talk about how systemic barriers contribute when things go wrong with PrEP adherence. Until next time, this is Connecting Care.