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CEI SH ECHO: PATIENT ENGAGEMENT IN PREP IN A SEXUAL HEALTH CLINIC

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CEI SH ECHO: Patient Engagement in PrEP in a Sexual Health Clinic
[video transcript]

00:09
Today, we're going to talk about patient engagement in PrEP in a sexual health clinic, in our sexual health clinic. We have no disclosures.

00:20
So, at first, I wanted to start by offering a big picture of some of the efforts and outcomes of the PrEP engagement process that we've experienced at the STD or sexual health clinic. This graph represents the period of time that we've provided at our clinic. The first bar is showing the number of intensive counseling sessions that have occurred for our high risk patients around PrEP. Whereas the next bar represents the number of unique individuals that were counseled. Therefore, we see that many patients have been counseled multiple times due to continued risk, before considering or accepting to engage in PrEP. And certainly there are numerous that will not choose this option. Next bar shows that only about a third of these individuals actually engage. And to clarify, we define engagement as the day when the pre-PrEP bloodwork is drawn, after consenting, implying that the patient is committed to starting PrEP. But as you see, only about 70% actually start their medication, and then only about 65% of these patients have returned for their one month follow up. So, obviously, we have some challenges to help our patients stay safe from HIV.

01:42
Okay, so this is just the basic demographic in terms of race of our PrEP client population. And you can see that for black and white it really is equal. We have about 16% Hispanic population engaging in or consenting to PrEP, and about 5% of other races. Okay, so this graph is showing the breakdown of patients starting and using PrEP in relation to acquiring three different STIs, gonorrhea, chlamydia and syphilis. We found that the acquisition of an STI or if the patient was informed that they were a contact to an STI, has been a great motivating factor in patients accepting and engaging in PrEP, as they may generalize risk of obtaining one STI to possibly being at risk of other STIs, including HIV. The blue bars represent the total number of PrEP patients treated for the specific STI. The red bars show us the number of patients that engaged at the time of the STI diagnosis. The brown bars are the number of patients that engaged at the time of learning that they were in contact with that STI. The purple bars are the number of patients with the diagnosis of a specific STI while the patient was already taking PrEP, and so we can surmise that there were barriers to condom use as part of the full risk reduction plan. And the last gold bars show the number of patients that may have experienced STIs, had at some point stopped PrEP, but then re-engaged in PrEP at a later time.

03:34
So once engaged, an ongoing challenge is to encourage and maintain adherence, because there are many adherence disruptions experienced for our patients. And these include change in insurance status, loss of job, temporary relocations for school or employment, lapse in communication due to lack of phone, transportation problems, changes in relationship status, feeling no longer at risk, missing appointments. Reminder calls are always given. Substance

use affecting choices, stressful busy lifestyle, and relationships, their partners, friends or family that are influencing their choices, unstable housing. But patients will frequently return to restart at a time that fits their ability or need.

04:29
So this can be a good segue into relating two scenarios where STI acquisition alone was not a significant enough motivator for the patient to engage in PrEP. The first scenario is rather lengthy. I'm in the wrong spot here, I'm sorry. Yeah, actually, before we go into those scenarios, I'd just like to talk a little bit about the barriers here to acceptance. There are different barriers for acceptance and for engagement. But for acceptance to consider starting PrEP, we have ambivalence regarding commitment to daily medication, concern for long term side effects, concern with present insurance coverage, believing obtaining insurance is too difficult, fear of a spouse or family member learning of PrEP use and its implications. The patient may be under 26 years old and on a parent's insurance, so they have confidentiality concerns. Their cultural taboos and social disapproval, homelessness or unstable lifestyle, not recognizing personal risks. A perception that other personal behavior changes will maintain safety, so deciding that they're not gonna have sex anymore or they will increase their condom use. And there are patients that have actually told us that they're afraid to be on PrEP, because then they know they're not going to use condoms. So that is something we have heard.

05:56
So then we also have barriers to actual engagement. So these are people that initially are recognizing the need to be on PrEP, but they still have barriers to actually start. So these can be folks that have no insurance at time of consent and are not willing to spend unexpected additional time in the clinic to receive the assistance at that visit, or they're not committed to a follow up appointment. Some patients will not provide the financial information required to obtain their financial assistance. Again, we have the fear of parental disclosure, among patients that might be on their parent's insurance. Then there are patients that change their mind, regarding being less anxious in security of home. And this we see more often, if the patient comes in for an STI test and has worry about it, they're at risk, they get their medication, they go home. And then they're home, they're feeling much more relaxed and not feeling the need to be on PrEP. Then those very anxious about getting HIV, but they also don't like to think about HIV every day, and don't want to take somethingt that is going to remind them of HIV. So these are some of the different things that we've heard from our patients. Transportation to return visits can be a problem, and certainly substance use interfering with maintaining appointments. I'm sure any of you that have worked with patients for PrEP have experienced many of these same issues.

07:35
Okay, so here's where I wanted to talk about our first scenario. So you can follow along with our timeline. So these two scenarios that I'm about to offer do have rather unfortunate endings, but follow along. So this 23 year old Caucasian male had HIV risks that included in MSM, IVDU, methamphetamine use, multiple partners, and multiple incidences resulting in STD clinic visits. He's a college graduate with a degree in the sciences and presently under his mother's insurance. Note at the time of his initial visit, the STD clinic was offering linkage services at other sites, but have later been able to offer full PrEP services within the timeframe presented.

So the patient represented to the STD clinic by referral from a Monroe County Health Department Public Health Representative, or a PHR, because he was a named contact of ELsyphilis and HIV. He was asymptomatic and was treated prophylactically with long acting Bicillin 2.4MU IM. His STAT RPR and HIV fourth gen rapid tests were both negative. He elected to start both his HAV and HPV vaccine series at this time as well. On risk assessment, he reported 10 male partners within the last three months and 20 within the past year. The patient was counseled for risk reduction, which included an invitation for referral for linkage to PrEP, as services were not yet available on site at the STD clinic. He consented to linkage and an appointment was scheduled for him for four days later at his site of choice. Upon receipt of his lab results post visit, multiple attempts were made to contact the patient for need of treatment for his positive pharyngeal and rectal gonorrhea results. He did not respond to any attempts to contact him. And since he had signed medical releases, it was learned that he had not attended his referral for HIV PrEP either. One month later, with the assistance of the PHRs, the patient was contacted and returned to the clinic for gonorrhea, still reporting asymptomatic. His fourth gen rapid HIV test resulted negative. The return dates for his follow up vaccine series were reviewed, and he was again counseled regarding PrEP availability with discussion of his missed appointment for PrEP engagement. He chose to schedule again for an appointment in two days. This was scheduled for him, but again he did not attend. He did not respond to any follow up calls. Five months later, a health department note was sent to the patient to remind him to return to the clinic for his due continuation of vaccine series. We never did hear from him. 15 months later, that patient returned to the clinic presenting with concern of a rash on his chest and abdomen that had already resolved two weeks prior. Of risks, he reported having 15 partners in the past three months and approximately 20 again within the past year. Although patient offered a history of methamphetamines and IDU within the past 12 months, he reported to be clean within the past seven months and was under a therapists care. His physical exam was unremarkable. His STAT RPR and fourth gen rapid HIV tests were both negative. He was then given his second dose of HAV and HPV vaccines. By this time, the STD clinic had already initiated the implementation of a PrEP program with PrEP clinical evaluation, prescribing of Truvada, and follow up done on site. The patient stated that he was still interested in engaging in PrEP and consented to be followed by the STD clinic. He was made aware that he would meet with the PrEP manager to complete insurance investigation for Truvada drug coverage. Of note, prior to this visit, the patient had expressed concern regarding his parents knowledge that he would be on PrEP, as he was under his mother's insurance. It was unclear as to what degree he had been contemplative about this, as he had previously consented to PrEP referral sites, but never showed for engagement appointments. At this visit, he conceded that he could now disclose this information to his mother. Therefore bloodwork was drawn for his pre PrEP screening, including an HIV 1 RNA PCR, due to having had unprotected sex within a week prior. His STD lab results received post visit were negative, with exception of positive pharyngeal GC, gonorrhea. The follow up nurse was able to contact the patient to inform him of need to return to clinic for gonorrhea treatment, which he did within days, stating that he was feeling hoarse and so was then treated. His PrEP labs received days later resulted with Hepatitis panel showing positive Hep C antibody and a Hep C ratio greater than 11. Again, there was an attempt to reach the patient and messages were left on four different occasions, with the fifth and sixth attempt being met with phone out of service. PHRs were notified, and three months later, the PHR was able to contact the patient and interview him for context regarding his most recent

gonorrhea diagnosis. The patient offered contact information for five of his eight named partners, including various chat rooms where he met partners. It's unclear to what extent there was discussion around Hep C during that exchange, and the patient did not respond to the clinic regarding the start of PrEP. Although clinic PrEP staff made additional attempts to contact the patient to follow up on his PrEP engagement and Hep C status, he neither responded nor returned to the clinic until seven months later. At that time, PHR had located him to inform him that he was named as a contact to gonorrhea and HIV. The patient did then return to clinic stating that he had mild sore throat for about a week. He reported six partners in past three months and again 20 in the past year. He stated to be clean from heroin and crystal meth for eight months. On physical exam he exhibited slightly enlarged bilateral cervical nodes with all other nodes within normal limits. He was given treatment as a contact to gonorrhea. But this day, his fourth gen rapid HIV tests resulted positive, followed by a confirmatory positive test from Wadsworth, the western blot. Upon receiving his STD lab results, he was positive for both pharyngeal and rectal gonorrhea, and fortunately already had been treated as a contact. When the nurse practitioner formed him of his positive HIV results, his response was quiet, sullen, and reserved, with no overt sign of great despair. He remarked that he was sadly aware that this was a possible outcome of his ongoing risk. An appointment was scheduled for him to attend HIV care, and it was confirmed that the patient did attend this initial, as well as follow up appointments at his HIV clinic, where he would also be followed for hep C. Additionally, two months later, the patient presented to the STD clinic again, by referral from a PHR as a named contact to HIV and syphilis. The patient was treated stat as a contact to syphilis, with all of his post-visit STD screening labs resulting negative. So here we see an unfortunate situation where we have a patient that states he recognized risks, yet there were barriers or issues unresolved that prevented him from keeping safe from HIV.

16:03

We have another scenario to follow, which represents a similar situation, and that although the patient seemed to objectively recognize risk based on frequency of STD acquisition, the risk does not subjectively appear to be a personal reality sufficient enough to create behavior change. This scenario, we have a 20 year old African American bisexual male who was counseled regarding PrEP on five different occasions. He was counseled as he met risk criteria for PrEP, but declined PrEP on his initial clinic visit. He presented asymptomatic, the post visit labs resulted positive for pharyngeal gonorrhea. He was contacted by phone and returned two days later with symptoms of sore throat and was treated appropriately for the gonorrhea. He returned to clinic five months later, and now accepted PrEP upon being diagnosed and treated as a contact to syphilis. He resulted HIV and syphilis negative. He was to return to clinic or contact us the following day with insurance information, as he was covered under his mother's insurance, but he had failed to do so. And he did not respond to any of numerous attempts to contact him. The patient did not return to us until nine months later, when he was very concerned after learning that he had been in contact HIV. His only complaint was that he was tired and achy for about three days. As he resulted HIV negative, he did engage in PrEP at this visit. And again, we define engagement as the date when the patient's pre-PrEP blood work is done. He was counseled extensively on PrEP use and importance of a scheduled one month follow up visit. His labs received post visit resulted positive for rectal gonorrhea, a PHR was able to contact him shortly and inform him of the need for gonorrhea treatment. The patient did not

return for another 15 days, at which time he presented complaining of rectal discharge for a week. It was learned from the pharmacy that the patient had waited over two weeks to pick up his PrEP prescription. On interview the patient was vague regarding his startup Truvada. The patient did not return for his one month follow up, nor did he respond to any attempts to contact him again. Patient's next visit was four months later. Presenting due to concern of contact to chlamydia. He was treated stat as the chlamydia contact and then resulted positive for rectal chlamydia. He tested HIV negative and consented to restart on PrEP, with extensive counseling regarding Truvada use,and additional risk reduction options. He again waited approximately two weeks to obtain his prescription. When phone contact was made to follow up on his Truvada use and remind him of his follow up appointment, the patient informed the caller that he was quote unquote, "in bed and would call back later." He did not call back and multiple attempts to reach him were futile throughout the next four months. Eight months later, following this last visit, the patient returned to the STD clinic with complaint of GI symptoms and concern of possibly had acquired rectal gonorrhea again. He reported having traveled out of town on two different occasions within the past month to see an ex boyfriend. Patient stated that he had not been taking any PrEP from any provider and that his out of town partner told them that he should be. At the visit, he was treated as an unconfirmed contact to gonorrhea as he was symptomatic and lab test results were pending. He did result with a positive pharyngeal and rectal gonorrhea, as well as rectal chlamydia. His preliminary and then confirmatory HIV tests were also positive on this date. The patient was very distressed upon learning his HIV results, and told his mother to come to the clinic to be with him. She arrived shortly and was very supportive to her son. An appointment was immediately made for the patient to be seen for HIV care at an HIV specialty center within two days, he did attend that appointment. But since his HIV diagnosis, this patient has also been diagnosed and treated for chlamydia at three different occasions, gonorrhea at two different times, and primary syphilis once. So these are just two of many scenarios that had very unfortunate results to give us food for thought. But I'd like now to turn this over to Nick who will offer some brighter examples of PrEP engagement outcomes.

21:06
Thank you. Yeah, thank you, Donna. Can everyone hear me okay?

21:10
I'm sorry? Oh, yeah.

21:12
Okay. Thank you. Yeah, so thank you, Donna. If you don't mind, could you just, perfect, perfect. Okay. So, just going back to the point Dr. Urban had made in the introduction, the cases that I'm going to present may not quite fit the New York State Health Alert in terms of demographics that are were seeing the increase from this time last year. And these two cases may appear slightly similar in terms of demographic information, but we did select them because I think they're pretty illustrative of the struggles that are faced by this specific population. Some of the challenges are cut across demographics as well, I would say.

22:02

So the first case here, at the very first clinic visit that we have with this patient, the patient reports really two things of note. One that there is commercial sex work going on, that they are selling sex for money or drugs. And the other thing to note is that the patient is reporting three long term chronic conditions to the nurses that are taking care of this patient during this health history taking. And right off the bat, this is of note as a barrier to acceptance and engagement. This is the patient having a real concern regarding possible drug side effects, drug interactions, from her very first visit. So something to note. About a year later patient returns, we see a marked increase in the number of sexual partners reported by this patient. And actually at this visit, we send PrEP labs off to the laboratory. So this patient has pending PrEP labs with us. Again, this is a year after our first visit with them. We send a first Truvada script after the bloodwork comes back looking okay. And after only two days of taking Truvada, the patient is reporting quote "intense dizziness" to the nursing staff. The first visit back since discontinuing PrEP, patient states they're no longer interested. The visit after that they've noticed a decrease in the number of sexual partners, are counseled for PrEP once again as they continue to sell sex for money and drugs. But still at that point, the patient remains contemplative for PrEP due to the dizziness they had experienced even after two days worth of being on PrEP. So now two years from the initial visit, patient comes in a few times for just some asymptomatic screenings it looks like. One of the visits is significant though, the patient reports at one of her clients removed the condom during sex and is again counseled regarding PrEP. But the patient remains pre-contemplative, so not quite ready, does maybe not necessarily see the benefit to restarting PrEP. Again, mentioning the blurry vision, foggy memory, something maybe having to do with the dizziness that she experienced the first time around. So you can see how even with an increase or decrease in number of sex partners or unknown partners, the side effects that a patient experience can remain a true obstacle for them even going forward with continued risk factors. So now skipping ahead three years now from the initial visit when we first spoke about this patient, when we first spoke about PrEPwWith this patient. The patient comes in with symptoms. They are contemplative for PrEP, so they are thinking about a bit more than the last visit. But the patient once again says to a nurse that they are concerned with the mental status changes due to what they perceive were drug interactions between Truvada and some of their other chronic conditions. It was at this visit that the patient met with one of our PrEP team members and we decided that it would be a good idea, maybe even to quell some fears or see if we could answer some of the specific drug interaction questions from the patient to consult with one of our medical directors, which we did. And the response we got from the medical director was that the side effects the patient was suffering may have had more to do with some of the pain medications that the patient was on for one of her chronic conditions, and that we should give Truvada another chance since the risk factors are persisting, and just to keep a close eye on side effects. But it was definitely worth another try. And so what we actually did was we printed this email exchange off and provided it to the patient to show them that, you know, we had taken the time, we had addressed this real concern of theirs, and here it is in writing from our medical directors from part of our team that we really think we should go ahead and it might be worth it. So sure enough, three years from first visit, patient is still reporting sex or money, and now they've decided with the help of our medical director that they would like to go ahead and try PrEP again. So now we have like I said, two years now from the first time they started PrEP, we have sent bloodwork once again. And just of note there has been now 12 clinic visits between the first time this patient was on PrEP and the second time this patient is going to be

on PrEP. About two years time has passed. So we felt really great about that, that we'd stuck with it, that we'd continue to counsel a patient whose risk factors had persisted. And so as you can see, down at the bottom here, the patient has continued to come to her PrEP visits. Most of the time she's remained asymptomatic, no other diagnoses. And the patient has reported PrEP adherence, and at the same time continued sex for money, sex for drugs, so we are more than happy to be able to provide the protection against that sustained risk. And I did put in quotations here just something, the first follow up visit after we had tried PrEP a second time, the patient just came right out and said that they were very happy that we had tried PrEP again. So that was quite nice. So yeah, this is a great success story. Again, 12 clinic visits in between the first time we tried PrEP and the second time, about a span of two years. But since we've onboarded this patient onto PrEP, they see no side effects related to Truvada. They're reporting adherence with their medication, and now have been on PrEP for more than six months. Problem free. So we're very happy with this.

28:35
And I do see a note in the chat. It would be helpful what is meant by contemplative and pre contemplative. Okay, yeah, so good point. Thank you, Marie. So this is part of, I believe, the motivational interviewing, stage based counseling that we use here at our clinic. So you'll see I made mention that the patient was contemplative for PrEP. It's something that we use to assess how ready a patient is to make a change in their lives, whether it's for safe sex or for onboarding onto PrEP. So as you can see, throughout even this one case, we had a patient who was pre contemplative, so someone who saw no need or had no interest in being on PrEP, or that protection from HIV. To someone who was contemplative, someone who was maybe now thinking about it a bit more, but definitely, there's been some barriers identified. And then all the way to where we are now where the patient is RFA, or ready for action. Someone who has identified the importance of PrEP, has addressed the barriers that were identified previously, and someone who's ready to make a change in their life, like I said, whether it's for safe sex or to get onto PrEP. So thank you and Dr. DeMarco did know in the chat that there's another session coming up on motivational interviewing, so they'll probably do a much better job explaining that than I will.

29:59
So Donna, if you could please advance to the next case here. Thank you. So like I said, the cases may appear similar. Similarly, in terms of demographics. Another 45 year old heterosexual female and other commercial sex worker. But some good things came up in this case. So one thing to note is that even before this primary conversation with the second patient here, the patient had been with us for about 20 plus clinic visits. So our staff was no stranger to this person, we'd seen them over years, since the middle to late 1990s up until present day, so we've been building a rapport with patient. And one thing I want to just point out is that onboarding or engaging patients onto PrEP, addressing these barriers and moving beyond them to get someone on to PrEP, I would say it's definitely a process and it requires building trust and building rapport with patients. I think one of the takeaways from this case would be that we had spent years talking to this patient. I would hope that the patient would trust us as their sexual health care providers, and that had something to do with the final outcome. So you can see the primary conversation we had with this patient had to do actually mostly with the risk that was

associated with their partner being a bisexual man, his drug use, and his history of incarceration and some of the risks that could bring into our patient's life. It wasn't until the following the year that we really started to talk about PrEP. I think at this point, we were finally able to offer PrEP as a clinic. I know Donna kind of alluded to that. But the patient came in with symptoms, we filled out a PrEP form, because the patient had been continuing their relationship with this bisexual partner. And at this point, that patient just stated flat out to one of the nurses that they wanted to take care of the HPV situation that they had going on, and the patient had insurance pending at this point. So no true insurance coverage. This brings up another barrier to acceptance and engagement. Patient definitely had some concern with present insurance coverage, 'what would it cost out of pocket if I didn't have insurance?' Patient may have believed that the insurance was too difficult to obtain. And one way that we would address this barrier, we actually are lucky enough to have a local partnership with legal assistance of Western New York, LAW New York. And they provide free health insurance navigation as the service they offer to this part of New York, so we're pretty lucky to work with them. So now, two years from primary counseling visit, patient is again in clinic with symptoms. The primary complaint being they were with a partner who was using needles, this partner is also bisexual, it was unclear whether this was her long term partner or not. And one of our patient's partners has HIV. So HIV in the mix, it sounds like. But also something a little alarming was that the patient did report to the nurse, that her partner was not allowing her to use condoms during these sexual encounters. Also, at this visit to note was the first time in more than 22 clinic visits now that the patient reported selling sex for money or drugs. So there was a lot going on at this visit. And you can start to see some of the revolving door that Donna talked about, some of those barriers that will persist. So for instance, you know, sex work is many things, I'm not sure if it's consistent work, I think that there could be rapid change in relationships. And obviously, in this scenario, there's definitely a relationship pressure, the partner not allowing condoms. There could be rapid changes in relationship status due to the number of sexual encounters and sex partners, but also a very stressful, busy lifestyle. We would think of it as like a barrier to adherence, or even engagement, you know, does the patient have time to come into clinic and sit and have their blood drawn, wait for the initial counseling and labs, and all that. So anyways, moving on from that, actually at that visit, the patient did agree to start PrEP by having the labs drawn, which was fantastic. We totally have supported that decision. Patient came back in for follow up and PrEP team members took another opportunity to meet with this person just to discuss, you know, remind them of adherence, how long you need to be taking the pills for protection, some possible side effects to look out for. And following up, a separate clinic visit, patient comes in with symptoms now and that patient has started PrEP, it's fantastic, but after only three or four days, the pills made the patient feel, quote unquote "weird." They mentioned that it had triggered some of their anxiety, but the patient also stated that they had been off their own anxiety medicines for some time. It was unclear why. So again, at this visit, there were a few things to address. And there's another barrier, you know, this patient clearly has some chronic conditions that need sorting out, we really wanted to encourage the patient, which we did, to get back onto their anxiety and depression medications to take care of that issue and treat it as equally important to the PrEP issue. And so really, that visit was about encouragement, it was about letting the patient know that we're going to accompany them through this tough time with their anxiety and with their depression. And also, get them on PrEP when they felt they had that under control. So again, encouragement, we made a return to clinic appointment. And the

patient did state though in the clinic visit that they did want to be on PrEP, there was no question about that. So it was nice, the patient at this third visit had discontinued after three to four days, with some encouragement and with some problem solving, we were able to get the patient back on and they have a follow up appointment scheduled. So one of the things I would like to say about this patient is that the patient really did take some initiative, that patient was very open and honest with us, it was more than what we could have asked of her. She showed a great understanding of the risks that she was facing, which is not always the case. But so far, so good. And I just I think this is illustrative of some patient's hesitation and confusion sometimes, but also they're genuine worry when when there's more than one risk factor involved, when there's more than one condition involved. How do I take care of separate things at once? So that's the second case, I hope that these were a bit more uplifting than Donna's. She was stuck with kind of some of the tougher cases there. But yeah, I think I hope that they've elicited some curiosity about or I hope they've given some answers about ways that we can address some of the barriers. So yeah, that's what I have for now. And I guess what I'll do is turn it back over to Dr. Urban if that's okay.

[End]