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HIV Treatment for Alcohol and Non-Injection Drug Users in El Salvador

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Abstract

Since the mid-1990s, many developing countries have introduced and expanded the availability of combination antiretroviral therapy (cART) to persons living with HIV (PLH). However, AIDS-related mortality continues to be high particularly among drug users. In this article, we present results from in-depth interviews with 13 HIV medical providers and 29 crack cocaine and alcohol using PLH in El Salvador. Providers endorsed negative attitudes toward substance using PLH and warned PLH that combining cART with drugs and alcohol would damage their livers and kidneys resulting in death. Upon diagnosis, PLH received little information about HIV treatment and many suffered depression and escalated their drug use. PLH reported suspending cART when they drank or used drugs because of providers' warnings. Substance using PLH were given few strategies and resources to quit using drugs. Messages from medical providers discourage drug users from initiating or adhering to antiretroviral therapy (ART) and may contribute to treatment abandonment.

Keywords

HIV; substance abuse; crack; PLH; cART; medical care engagement; medical providers' attitudes; El Salvador

Introduction

Since the mid-1990s, many developing countries have introduced and expanded the availability of combination antiretroviral therapy (cART) to those infected with HIV (Murillo et al., 2009; Murillo et al., 2012; Murillo et al., 2010). Although many of these countries, including El Salvador, offer cART free of charge, AIDS-related mortality continues to be high due to late diagnosis of HIV infection, late entry into medical care and poor medication adherence (Barnighausen, Chaiyachati, Peoples, Haberer, & Newell, 2011; Charurat et al., 2010; Mills et al., 2006). All of these factors can increase the potential for

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persons living with HIV (PLH) in resource-poor countries to infect others because of their higher plasma viral loads (Cohen et al., 2011; Mayer & Krakower, 2012), increasing HIV incidence in populations with a high prevalence of HIV and risk behaviors.

The El Salvador Ministry of Health (MINSAL) began to offer free cART in January 2001. However, mortality due to AIDS is the second leading cause of death in hospitals in El Salvador for the 25 to 59 age group and the third leading cause in the 20 to 24 age group (Murillo et al., 2012). By December 2009, 8,348 people were receiving free access to cART. According to the World Health Organization (WHO), there are 16,000 people in need of therapy in El Salvador, indicating a present coverage of around 53%. Furthermore, in a study conducted in one national HIV clinic, 20% of patients were lost to care between June and September 2011, 20% had stopped taking antiretroviral therapy (ART) within the first month of initiation, and almost 40% abandoned ART in the second month (Alvarado, de Alfonso, & Gonzalez, 2012). A qualitative study with HIV health providers and people living with HIV (PLH) who had received cART in El Salvador suggests some reasons for the high loss to medical care and cART abandonment (PASMO, 2012) including lack of transportation, stigmatization, and lack of respect for patient confidentiality by hospital staff. This study also suggested reasons for delayed initiation of cART including PLHs' lack of awareness that HIV was a chronic condition that could be managed after diagnosis, a lack of comprehensive pre- and post-test counseling in sites where they received the test and no referrals to HIV clinics after diagnosis. Participants of this study, however, did not include active substance users. Substance using PLH may have more and different barriers to medical care and adherence.

In both developed and developing countries, including El Salvador, drug users are a population with a high prevalence of HIV infection, late diagnosis, poor linkage to care, and suboptimal adherence to cART once in care (Kober et al., 2011; Milloy, Marshall, et al., 2012). In El Salvador, injection drug use is rare and alcohol, marijuana, and crack and powdered cocaine are the most frequently used drugs. Many studies have demonstrated the link between problematic drug and alcohol use, sexual risk behaviors, and HIV infection (de Azevedo, Botega, & Guimarães, 2007; Harzke, Williams, & Bowen, 2009; Inciardi, 1993; Ratner, 1993). Our own research shows prevalence rates among crack users in El Salvador (7%; Dickson-Gomez et al., 2013) that are similar to prevalence among other groups in which the epidemic is concentrated such as Men who have Sex with Men (MSM) (10.8%), Commercial Sex Workers (CSW) (5.7%), and trans-women (19.7%; Ministerio de Salud Publica y Asistencia Social, 2011).

Most research on cART adherence has been conducted with injection drug users (IDUs). However, IDUs and non-injection drug users (NIDUs) have been found to be less adherent than non-drug users in numerous studies (Doshi et al., 2012; Mann et al., 2012; Milloy, Monaner, & Wood, 2012; Vogenthaler et al., 2011; Wood, Milloy, & Monaner, 2012). Compulsive drug-seeking behavior is but one factor among many that is associated with suboptimal ART adherence (Wood et al., 2012). Additional social and environmental predictors of poor adherence among drug users include homelessness (Doshi et al., 2012; Milloy, Kerr, et al., 2012; Milloy, Marshall, et al., 2012), incarceration (Mehta et al., 2007; Milloy et al., 2011; Milloy, Marshall, et al., 2012), lack of legal income (Piketty et al.,

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1999), and particularly among crack users, interpersonal violence (Kalokhe et al., 2012) and food insecurity (Shannon et al., 2011; Weiser et al., 2008). Many of these same factors are also associated with sexual risk behaviors. Depression, negative attitudes toward antiretroviral medication, and low self-efficacy for taking antiretroviral medications as prescribed are also associated with suboptimal adherence among substance users (Arnsten et al., 2007).

While personal and structural factors have been frequently studied in research to explain the poor clinical outcomes of substance using PLH, research has also highlighted the role that providers' attitudes can have on cART prescribing patterns (Knowlton et al., 2010; Maisels, Steinberg, & Tobias, 2001; Westergaard, Ambrose, Mehta, & Kirk, 2012). However, studies regarding provider prescribing practices have mainly focused on provider attitudes toward IDUs. A study conducted in HIV primary care sites in 10 U.S. cities found that IDUs were less likely to receive cART compared with NIDUs (Gebo et al., 2005), in spite of current WHO guidelines that drug injecting should not disqualify patients from cART eligibility, and that addiction treatment should not be required before cART initiation (WHO, 2006). Studies have found that physicians are more likely to delay starting cART for patients who inject drugs (Westergaard et al., 2012), and that physicians with negative attitudes toward IDUs were significantly less likely to initiate cART among IDUs than those with positive attitudes (Ding et al., 2005).

Although less studied, it is likely that physicians may also be less likely to prescribe cART to users of non-injection drugs or alcohol. Studies have shown that medical providers have negative attitudes toward alcohol and other drug users (Ahern, Stuber, & Galea, 2007; Ronzani, Higgins-Biddle, & Furtado, 2009). These negative attitudes can be thought of as a result of a process of social stigmatization. Stigma, although variously defined, can be broadly defined as "a characteristic of persons that is contrary to a norm of a social unit" where a norm is defined as a "shared belief that a person ought to behave in certain ways at a certain time" (Stafford & Scott, 1986, pp. 80–81). Substance use disorders are stigmatized by health care professionals through the process of "moralization" of the illness. In the case of substance use, people who use alcohol and other drugs are not only seen as behaving in ways that are deviant, but they are often considered responsible for the problematic behavior (Ronzani et al., 2009). The process of stigmatization can result in the exercise of power over stigmatized groups as the attribution of personal responsibility is often related to the health professionals' willingness to offer help (Heathertorn, Kleck, Hebl, & Hull, 2003). Alcohol and other drug users may believe that most members of society, and their health care providers in particular, believe negative stereotypes about drug users, for example, that they are weak, immoral, and cause a risk to society, a process called perceived devaluation (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Internalized stigma, otherwise known as alienation, occurs when alcohol and other drug users accept the negative stereotypes about themselves to be true (Ritsher, Otilingam, & Grajales, 2003).

Many providers delay initiating cART with substance users due to their belief that substance using patients will not be adherent (Maisels et al., 2001). While substance use and other clinical factors such as depression correlate with non-adherence, the ability of physicians to predict adherence in individual patients is limited (Stephenson, 1999). Furthermore,

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appropriate support services such as treatment for mental health and substance use disorders can significantly improve adherence among substance using PLH (Kapadia et al., 2008; Rosen et al., 2012). Unfortunately, treatments for substance use and mental illness is inadequate or lacking in many developing countries (Bobrova et al., 2008; Perngparn, Assanangkornachai, Pilley, & Aramratanna, 2008; Wang et al., 2007), and few interventions for substance using PLH have been developed or evaluated in developing countries (Mayston, Kinyanda, Chishinga, Prince, & Patel, 2012).

Qualitative studies of engagement in care are essential to better understand the barriers to care faced by substance using PLH, to expand conceptual understandings, and to develop and improve HIV treatment and adherence for this population. Some qualitative research has begun to look at the HIV treatment continuum, or "cascade," from patients' perspectives (Brion, 2014; Christopoulos et al., 2013; Quinlivan et al., 2013; Rao et al., 2013). The HIV treatment cascade includes testing, entry into HIV care, retention in HIV care, cART initiation, and cART adherence (Meyer, Althoff, & Altice, 2013). All steps along the cascade are needed for PLH to achieve viral suppression. However, little qualitative research has looked at the experiences of substance using PLH along the HIV continuum. Fewer still have examined the experiences of substance using PLH in developing countries where substance abuse and mental health treatment are limited (Wang et al., 2007).

The current article draws from qualitative interviews with PLH and HIV care providers from multi-disciplinary teams working in HIV clinics that are part of El Salvador's national health care system. We explore the role of substance use, drug-related stigma, and lack of knowledge of effective cART treatments on PLH linkage to care, cART initiation, and cART adherence.

Method

In October 2012 through April 2013, we conducted in-depth interviews with 13 personnel who are part of the interdisciplinary teams in two national HIV clinics in the San Salvador Metropolitan Area. All government-run HIV clinics contain, at a minimum, a team consisting of a physician, nurse, pharmacist, psychologist, and social worker. Some clinics also include peer health promoters. Personnel interviewed included at least one of each type of professional per clinic. In-depth interviews covered their training, how they became involved in HIV work, their roles in the multi-disciplinary team, and barriers to medical care and cART initiation and adherence. In particular, we asked team members about their experiences in working with PLH who have substance use problems, and their opinions of what could be done to improve medication adherence and health in this population.

We also conducted in-depth interviews with 29 substance using PLH. PLH were selected to reflect diversity and included PLH who were currently using alcohol and other drugs and those who were in recovery, those currently seeing a medical provider and those who were not, those who were on cART and those who were not, and time since diagnosis. Participants reported having used or currently using alcohol, crack, and cocaine. The majority were poly-substance users. None reported injection drug use. Several participants had been diagnosed with HIV less than a year prior to the interview, whereas others had lived with HIV for

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several years. Interviews covered participants' knowledge and attitudes about HIV before their diagnosis, reasons for getting an HIV test, reactions upon learning they were HIV positive, their decisions about whether or not to seek medical care, their experiences with HIV treatment and cART, experiences with stigma and discrimination, and strategies to adhere to cART. Participants were asked how their drug use and sexual behavior changed over time as a result of their HIV diagnosis, and their experiences with medical personnel's reactions to their substance use.

All in-depth interviews were conducted by a Salvadoran psychologist, trained and experienced in conducting in-depth interviews. Interviews were audio-recorded, and written informed consent was obtained from all participants. This research was approved by the Institutional Review Boards (IRBs) at the Universidad Centroamericana José Simeón Cañas and the Medical College of Wisconsin.

Analysis

All interviews were transcribed verbatim in Spanish and entered into MAXQDA qualitative software for analysis. The first author, a medical student, and the Salvadoran research team collaboratively developed and refined a codebook to reflect broad content areas. After the code-book was finalized, the research team collaboratively coded interviews, resolving differences of opinion collectively. Interview excerpts related to themes were then exported and compared among participants paying particular attention to code overlaps, for example, reactions to diagnosis and substance use. Final interpretations were checked with the research team until all were satisfied with the explanatory model presented in this article.

Results

Learning You Are HIV Positive

The most common initial response of PLH upon learning they were HIV positive was thinking that they were going to die and had little time left to live. Very few had any knowledge of effective treatments for HIV. When describing their reasons for seeking a test, 12 of the 29 already had symptoms. Some suspected that it might be HIV and sought a test. Others were recommended a test after seeing a medical provider for their symptoms. An additional 3 sought an HIV test because they discovered that a sexual partner had HIV, 2 had it as part of routine laboratory tests before an operation, and 1 as part of her prenatal care. In addition, 12 of the 29 had never had an HIV test before their positive test and only 2 described having an HIV test regularly based on their perceptions of their risk as commercial sex workers. Thus, it is not surprising that most PLH in our sample had outdated notions of the possibilities of living with HIV, and many described knowing little to nothing about HIV in general. For some, prior knowledge of HIV was limited to familiarity with PLH living in their communities, who were perceived to be contagious and were consequently avoided.

> Interviewer: What did you know about HIV before you were diagnosed as HIV positive?
>
> Male participant: I knew practically nothing, that it was a fatal illness, that on discovering it you died immediately … You ended up all skinny, without any hope.

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> Interviewer: Who had given you information about [HIV]?
>
> Male participant: Nobody, just that I had seen certain cases [of HIV] on the street. The cases that you see of people who are like that so they said, "That guy has AIDS. Don't get close to him, he's contagious." So I saw people die like that.

Upon receiving their diagnosis, many participants reported that they were not given information about effective treatments or referrals to HIV clinics. Thus, many still believed that HIV was a death sentence after learning they were HIV positive. The participant above, for example, reported that he received no information regarding cART or a referral to medical care after receiving his result.

The two participants who reported regular testing were gay men who engaged in commercial sex work. They had attended non-governmental organizations (NGOs) that worked to prevent HIV among men who have sex with men and female sex workers. These participants received information about the symptoms of HIV and sexually transmitted infections (STIs), how to prevent infection, and the necessity of regular testing.

> Interviewer: What did you know about HIV before you were diagnosed as HIV positive?
>
> Male participant: Well, really I knew about it all. For 14 years I was volunteering in NGOs. I participated in talks. I brought my friends along. In other words, I knew about it all and I also had the experience of losing friends because [they were infected with] that disease … [I knew] how it's transmitted, how to avoid transmission … the methods that you should use, to look for help if you turn out positive. Really I had all the information, and not just about that disease but about all the different STIs.

As he explained above, this participant had already learned that medical care was available to him prior to receiving an HIV diagnosis. Thus, he immediately sought medical care.

> Interviewer: And after you were diagnosed with HIV, did your ideas change?
>
> Male participant: Yes, my whole life changed … because I knew that I had to take care of myself better, that I had to change my lifestyle that I had to eat well, not run around, all this changed my life. It was hard but maybe the help of my friends made me stronger … I can't tell you I've suffered because really I haven't suffered. I took the news calmly and maybe I was looking for it [HIV] in spite of all the information I had. But you have to keep going forward.

While this participant expresses some recognition of how his behaviors contributed to his becoming infected in spite of all the information he had received, he was able to take the news "calmly," looked for medical attention, and received support from his friends. In contrast, those who had little information about HIV and did not receive any information about ART or medical treatment when given their HIV diagnosis often described feeling extremely depressed. Several participants described thoughts of suicide or actual suicide attempts. This delayed their entry into medical care, as many saw no point in seeing a doctor for an incurable disease, as expressed by the participant below.

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> Interviewer: Have you had any changes in your life because of your diagnosis?
>
> Male participant: Yes … To begin my self-esteem. I felt like a worthless person that I am not of any value. I'm condemned to die gradually. How can I explain? I feel inside that I have been devalued. Those have been the changes …
>
> Interviewer: Have you sought medical treatment?
>
> Male participant: No.
>
> Interviewer: Why haven't you sought medical treatment?
>
> Male participant: Stupidly, I tell myself I already did it, there isn't any coming back. I'm already on the list [to die]. I don't think I'm coming out of this. My morale is very low. I don't know why I would have to look for help. I don't want to look for it because I say, "What for?"

Many blamed themselves for their infections contributing to their feelings of depression and hopelessness. Some participants reported isolating themselves from family or friends. For some, like the woman below, this was due to the erroneous belief that they could infect others by casual contact. Many others feared rejection from family members due to their diagnosis. Many also reported increasing their substance use for years after their diagnosis.

> Interviewer: How has your life changed?
>
> Female participant: It has changed a lot. For example I'm not with my children anymore. They live somewhere else because I don't want to infect them.
>
> Interviewer: Has your use of drugs or alcohol changed at all?
>
> Female participant: On the contrary. Before I didn't do anything like I do now. It pushed me more into that [drug use]. I didn't do anything like I do now.

For some, this increased drug use and depression resulted in a delay of years between diagnosis and seeking medical care. For example, the participant below waited 5 years until entering medical treatment and beginning a process of reducing his drug use and taking care of himself.

> Interviewer: Have you had any changes in your life because of your HIV diagnosis?
>
> Male participant: Yes, changes in terms of taking care of myself because I had to stop using drugs, stop using alcohol, I started to realize I needed to be in control and begin some sort of change in me … I am more aware because in those five years that I knew my diagnosis, I still kept drugging, I continued drinking alcohol because I said I already know what I'm going to die of. There weren't any dreams to realize anymore, just waiting for that day.

The participant above sought HIV medical care after entering a rehabilitation center. He shared his HIV positive status with the director of the center who then encouraged him to seek medical treatment and accompanied him to his first visit.

This treatment delay was not inevitable, however, as other participants who knew little about HIV before their diagnosis reported linking into medical care almost immediately. The

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difference between these participants (approximately a quarter of the sample) and the others was that they received immediate referrals to the hospital. In addition, many received at least some preliminary information (and sympathy) from their HIV test counselors.

> Interviewer: What was your first reaction upon learning the test result?
>
> Female participant: Well, like I said it was to cry. At that moment I cried and the counselor there told me, at the health clinic where I was diagnosed, she said, "You are going to go to a hospital. You're going to see a psychologist. There she's going to explain what is happening to you, what can happen" and that's how it was. I went to the hospital two days after diagnosis. A psychologist talked with me about the topic [HIV]. She even treated me like I was a kindergarten student. She made dolls and made me see that life, life is priceless, if and only if we value it and the opportunities that they're giving us with the medication more than anything …

PLH who sought medical care immediately after diagnosis also benefited from counseling by providers on how and whether to disclose their HIV status to family and friends. In addition, the in-depth counseling provided by psychologists emphasized how taking antiretroviral medications could prolong and increase quality of life, which were important motivators to staying engaged in HIV medical care and adherent to medications.

Medical Providers' Attitudes Toward Substance Users

As mentioned in the "Introduction" section, in November 2001, El Salvador passed the Law and Regulation for the Control and Prevention of HIV which mandated free access to antiretroviral medications for PLH for the first time. However, access to cART remained limited due to medication shortages and implementation mechanisms, for example, trained medical personnel and laboratory supplies. As access to cART was scaled up in Latin America, researchers and providers also worried that poor adherence to cART might cause drug resistant strains of the virus (Chequer, Cuchi, Mazin, & Calleja, 2001). In this context, an unofficial policy of HIV providers working through the Ministry of Health was to require PLH with substance abuse problems to become abstinent from drugs or alcohol. This unofficial policy is confirmed by the participants in the current study, such as the participant below who was diagnosed in 2000.

> Interviewer: How long ago did you start your treatment?
>
> Male participant: Eight years ago.
>
> Interviewer: How did you decide to start treatment?
>
> Male participant: I told the doctor to give it to me because I didn't want to die …
>
> Interviewer: Did you feel like you were part of the treatment decision?
>
> Male participant: Yes … because they weren't giving treatment to people who were using drugs and I was afraid of that. I told the doctor to give it to me and you can't fool the doctor, right, because they do blood tests. He knew very well that I was using drugs but even so I told him to give it to me because other friends came that used drugs. They died because of that. They didn't give them the treatment because they used drugs.

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Since 2009, cART has been available to all PLH regardless of whether they use drugs or not. However, most medical personnel still recommended, often very forcefully, that PLH abstain from any alcohol or other drug use before initiating cART. Many believed and told patients that taking cART while using alcohol or other drugs was contraindicated because the combination would cause liver and kidney damage that could lead to death.

> Interviewer: What instructions do you give to people who are drug addicts or alcoholics?
>
> Female provider: From the first moment that we discuss the topic we let them know that every medication passes through the liver and kidneys. Alcohol also passes through the liver and kidneys so I tell them that it's an atomic bomb to use alcohol and medication … I tell them to look for help in Alcoholics Anonymous so that they can give them some guidance about how to stop using alcohol.

Some medical providers, particularly those who were not physicians such as social workers and psychologists, recommended suspending treatment during times of relapse because of this belief.

> Interviewer: What information about treatment do you give to people who are drug addicts or alcoholics?
>
> Female medical provider: We explain the importance and the fact that they have to avoid consuming them both at the same time … So they prefer to stop the medication and continue drinking. They suspend their treatment. When they feel a little better they come back and then they relapse again.
>
> Interviewer: What do you think about [antiretroviral] treatment of HIV positive drug and alcohol users?
>
> Female medical provider: I would wait until the alcoholism or the drugs are a little more under control before initiating treatment because if not, we are hurting them more.

Many medical providers believed that alcohol or other drug using PLH could not be adherent to cART. As seen below, this disbelief in substance using PLHs' ability to adhere to treatment stemmed, for some, from stigmatizing attitudes toward alcohol and other drug users. It was not simply that the chaotic lives associated with drug use might interfere with medication adherence. Some medical providers felt that drug and alcohol users had serious flaws in their personalities that made it impossible for them to take responsibility for their own health.

> Interviewer: What could be done to improve adherence to [cART] treatment?
>
> Male medical provider: Recovery from their addictions and getting them into a group therapy process. Therapies for addicts like the 12-step process that causes a change in their personality, those character defects they may have like irresponsibility, lack of discipline, not loving themselves …
>
> Interviewer: And to improve their quality of health and the effectiveness of treatment?

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> Male medical provider: First, as I said, recovery because without that they're not going to be adherent. Maybe efavirenz is the only one [antiretroviral drug] that they would like because they begin to hallucinate and have vivid dreams, but I maintain that first it's got to be recovery.

Like the provider above, many providers recommended drug or alcohol treatment but with less damning views of alcohol and other drug users. However, few had any experience or training in drug or alcohol treatment. As one provider said,

> I would say that we need to have a more specialized area in mental health with a little more experience, and more training in order to help keep [PLH with substance abuse] in treatment. Unfortunately, we don't have this specialty. I do what I can and what is within my reach, but I feel like there should be something more.

Given these limitations, the advice of many providers to substance using PLH was simply to stop using drugs. Others referred patients to 12-step programs or started such programs in the HIV clinics. Psychologists and social workers expressed frustration at the low efficacy of their efforts to individually treat substance using PLH or to start 12-step groups in the clinic.

> Interviewer: What has been your experience with HIV positive drug and alcohol users?
>
> Female medical provider: Since 2010, I and the psychologist decided to start a group for alcoholics and [people with] problems with drugs. We had two or three meetings. From then on, the meetings became individual because they stopped coming … But it's hard, it's difficult. At the moment I have only one young man who told me, "Doctor, let's start a good adherence," but suddenly he fell off the wagon for two weeks. He came to start again and suddenly he fell off the wagon again. This is the fourth relapse he's had and he hasn't yet appeared again.

It is unclear why the Alcoholics Anonymous groups that were started in HIV clinics did not work. Some substance using PLH simply may have not been ready for total abstinence from alcohol or other drugs, as 12-step programs demand. Some research suggests that only between 5% and 10% of substance users are able to achieve sobriety through 12-step programs, with the vast majority dropping out (Dodes & Dodes, 2014). Other substance using PLH may have needed a more intensive program. However, many medical providers mentioned that there were few drug treatment programs that would accept PLH. In addition to having difficulties finding drug treatment programs that would accept PLH, some providers also mentioned the poor quality of most drug treatment programs, most of which are faith-based and rely on residents' work, such as selling trinkets on the street or on buses, to support the costs of the program.

> Interviewer: What could be done to improve adherence in these users?
>
> Female provider: What we could do, perhaps increase the participation, first maybe of the state, because there are these clinics but we see their limitations … I asked [one of my patients] "Why don't you go to a shelter?" "They use us to go sell. They use us to make food. It's true that we need to keep busy but we need a place where they aren't using drugs as well." Maybe having a shelter just for people with HIV, with problems with addiction, maybe that would be one of the ways to help with

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> adherence. Like he told me, "They give me twenty pencils to go sell and I can say 'I sold ten' and the rest I use to buy drugs or alcohol." Also [in shelters] we see them discriminated against because the director often isn't very discreet in keeping a secret [of the PLH's serostatus].

Many faith-based treatment centers in El Salvador are formed by people who recovered from substance use through their involvement in churches. Most staff members have little training in drug treatment, beyond staff and minister's previous experiences in recovery (Dickson-Gomez, 2012; Dickson-Gomez, Bodnar, Corbett, Guevara, & Rodriguez, 2010). In addition, few have formalized treatment plans. Rather, treatment focused on prayer and work activities and creating a family-like social environment. As the medical provider above mentions, however, work outside the shelter or ministry can put residents in danger of relapse, both because of the ease in pocketing money to buy drugs and because the neighborhoods in which they sell items are also areas where drugs and alcohol are easily bought.

Given the limitations of substance abuse treatment for PLH, a minority of providers embraced a harm reduction philosophy by trying to give PLH the tools to reduce their drug use and continue to adhere to cART. The opinion expressed by the physician below was uncommon, as most providers continued to recommend total abstinence from alcohol and other drugs before taking cART due to their erroneous beliefs in the harmful effects of mixing any amount of alcohol or other drugs with cART.

> Female provider: Now we have an Alcoholics Anonymous group that helps us in some ways, but not all the patients go. Basically, the treatment is given during the consultation and maybe it's more understanding and more merciful not to put a bigger burden on their addiction, more tolerance. I don't prohibit my patients from using alcohol, but I lower their "dose" [of alcohol]. There are people who can reduce [alcohol] or drugs gradually.

Experiences of Drug Using PLH: Achieving Sobriety

Some participants found that becoming diagnosed with HIV along with doctors' and other providers' advice to stop using drugs and alcohol provided sufficient motivation for them to abstain from alcohol and other drug use. Some, like the participant below, saw becoming infected with HIV as positive as it allowed her to re-examine her life and stop the destructive behaviors that were damaging her health and relationships.

> Interviewer: Has your use of drugs or alcohol changed in any way?
>
> Female participant: Yes. When they gave me my diagnosis, well in spite of getting a little upset, I gave thanks to God because I said, "God, I thank you because HIV came into my life, and if it hadn't been for that maybe I would already be dead" because before I knew my diagnosis, I was losing myself in a way. My mom couldn't stand me anymore. She said, "Get out! Get out! I don't want you here anymore," because I would come home really drunk before sunrise … I was drinking every day and not just beer but hard liquor … I said "Thank you God because through this illness you have put a stop …," because thanks to God since I learned my diagnosis, I said I'm not going to drink anymore, because the doctor

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> told me "I'm going to give you a medication," and they started to explain to me that I couldn't smoke, I had to leave my vices completely. I had to stop everything that I did in order to start the medication and take it like you should. So from there I started and up to today, I haven't put a cigarette in my mouth, much less liquor.

Others found it difficult to remain drug and alcohol free and experienced relapses (some participants reporting several) during which they were unable to adhere to their medications. Often these relapses were precipitated by serious depression. El Salvador has even fewer resources available for treating mental illness than for drug dependence. In fact, for some, medical providers' instructions to abstain from drugs and alcohol may have seemed overwhelming and may have contributed to their depression.

> Interviewer: [Has your] drug use [made it difficult to adhere to treatment?]
>
> Male participant: Yes, a lot, because I like to use a lot and so abstaining from use for me is a huge effort. It isn't so easy.
>
> Interviewer: Talk to me a little about that situation?
>
> Male participant: Here is the treatment that you are going to have to take religiously in this and that way but you have to stop alcohol, drugs and sex. For me it was difficult because … abstaining from that was like they were taking away my air. So there was a moment of doubt for me. Do I continue treatment or continue destroying myself? One week I went to treatment but one night I felt really depressed and had those evil thoughts of suicide with a lethal poison … In the place on the street where I slept there was a little dog that for me was my best friend. The little dog pulled my pants when I was going to take the poison, and I spilled … God showed himself through that little animal. So I said that it's better to take this medication.

Although some were able to achieve abstinence eventually, many like the participant above reported that taking control of their drug and alcohol use was more difficult than learning they had HIV.

> Male participant: Right now I'm clean, ten months. I have had relapses in the process because in fact I am in the process of recovery and it's been hard for me. Maybe it's even been harder for me than accepting my reality of life with HIV, my dependence on drugs and alcohol. But [I take it] day by day since January of this year, 2012. Uh huh, that's ten months.

Patient–Provider Relationships

Medical providers' admonition to abstain from alcohol and other drugs, aside from causing frustration and a sense of failure among PLH, can also damage the patient–provider relationship. Participants reported not talking about drug and alcohol relapses or continuing drug and alcohol use with medical providers for fear of disappointing them or recriminations. Some reported that they had spoken with medical providers about their drug and alcohol use in the past, but decided not to speak to them after being "scolded." In some cases, doctors threatened to take away patients' medications if they continued to use drugs. For the participant below, this led her to switch doctors as she felt that the doctor was more

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concerned about the expense of the medication than about her health. However, after this first experience, she refrained from telling her current doctor about her alcohol and other drug use.

> Interviewer: Did you ever talk with your doctor about your alcohol and cocaine use?
>
> Female participant: Yes, I am a person who tells the truth. That is my truth and why am I going to be hiding it? I told the doctor.
>
> Interviewer: How did she react?
>
> Female participant: You know, I changed from the doctor that I told. I've been with the new one for like six months. I haven't told her what I experienced before. But the one before … I came with a lot of needs and she didn't have time if I didn't have an appointment. I told her [that I had relapsed] and she says, "They already told me what you're doing, that you're drinking and I don't know what." "Look doctor, it's true," I told her and "So what are we going to do with the medication. Should I take it from you?" "That's up to you," I told her, "if you take them or leave them with me, but I think that my right is that you have to give them to me whether or not I take them. You have to give them to me." And she said, "Why? So that you can open a pharmacy?" "No," I said, "But some day I'm going to have to take them." So I felt that she didn't care and that what hurt her more was that she was losing the medication. So from that experience I decided to switch. I was better [not using so much] when I decided to switch. The crisis had passed, well the first and last I believe because I haven't relapsed.
>
> Interviewer: That was the reaction of your old doctor. You haven't said anything to the one you're with now?
>
> Female participant: I haven't told her anything.

Although the participant above does not talk about why she has not discussed her past drug use with her current doctor, her past experiences may have made her reluctant to trust her doctor with this information, especially because she is not currently using. Thus, providers' negative reactions to substance use can continue to have a long-term negative impact on trust in the provider–patient relationship, even after switching providers.

Others, rather than switching providers or consulting with psychologists, opted not to continue in medical care after scoldings.

> Interviewer: And have you talked with your doctor about your drug and alcohol use?
>
> Informant: Yes.
>
> Interviewer: What did the doctor say?
>
> Informant: He scolds me. He scolded me.
>
> Interviewer: Did he give you any kind of advice about your drug use?
>
> Informant: No, but I haven't been to the hospital in a long time.

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Medication Adherence

As discussed above, medical providers typically warn PLH of the dangers of mixing drug and alcohol use with cART. This has the perhaps unintended effect of many substance using PLH taking medication "vacations" while they are actively using alcohol or other drugs. In some cases, participants stopped taking medications for long periods of time when they had serious relapses, as seen above. Other PLH, however, who did not seem to have serious alcohol or other drug dependence issues, described stopping medication for 1 or 2 days when they decided to go to a party and thought they would be drinking alcohol. At least one medical provider quoted above actually recommended that PLH suspend taking medication if they were going to use drugs or alcohol.

> Interviewer: It's not so easy to adhere to your medication. How often do you stop taking your medication?
>
> Female participant: Every two, three months for a day and the next day I go back to taking it. I don't stop. I don't go for more than two days without taking my medication.
>
> Interviewer: What are the reasons you have stopped?
>
> Female participant: Always because I am going to parties and I drink a beer or something. It's not because I forget or because I didn't bring it with me. It's because you can't take it with alcohol.
>
> Interviewer: And on those occasions did you use drugs?
>
> Female participant: Yes, cocaine.

Most participants believed the dire warnings from medical providers about mixing cART medications with drugs or alcohol.

> Male participant: When I am not using, I take it just like they prescribed. When I am using I don't take anything because I am afraid of poisoning myself.
>
> Interviewer: And how long do you stop taking them?
>
> Male participant: At most for a week.
>
> Interviewer: And right now how are you with your [HIV] treatment?
>
> Male participant: I'm not taking it.
>
> Interviewer: Since when?
>
> Male participant: Since Monday I'm not taking the treatment. Possibly Monday I will start again if God permits me to live.

Some participants continued to take their medication even when using in spite of providers' recommendations. For example, the participant below had been advised not to mix alcohol and other drugs with cART, but after doing it and not seeing an adverse effect, he was skeptical of doctor's warnings of harmful drug interactions.

> Interviewer: Has your use of drugs or alcohol changed in anyway?

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> Male participant: Not so much (laughs) because there are times when I want to drink, I drink, and, but the drugs I only use when I drink, if not I don’t. But at first I was afraid because they told me [not to take drugs with cART] but since I don’t feel that anything happened to me, I keep using.

When not taking deliberate cART vacations due to providers’ recommendations not to mix alcohol and other drugs with cART, substance using PLH had generally good adherence. Very few described forgetting medication. Some described using strategies like taking the medication at the same times every day or with meals, or writing down when they needed to take pills.

> Interviewer: In general how do you remember that you have to take your pills, your medication?
>
> Informant: Well, I am always right on time. I say now it’s time for my pills … and I grab the bottle and in it goes.
>
> Interviewer: But how is it you’re on top of that?
>
> Interviewer: Well now I remember when I am hungry and I say now it’s time to eat so that’s how I remember my pills.

Others used alarms on their cell phones.

> Male participant: In my case, I take it [cART] at eight in the morning on the dot. On my cell, I have the alarms at eight at night the other, and nine thirty or ten the next pill which is the last one.

Another participant who had a tendency to forget to take his pills due to long-term alcoholism enlisted the support of his daughter to help him remember.

> Interviewer: How do you remember to take your pills?
>
> Male participant: I have it written down on a little piece of paper how many hours, how often. The paper I keep with my daughter. It’s possible that I forget because the brain of an alcoholic isn’t like a normal brain, so what I do is read the paper and my daughter helps me. She tells me, dad it’s time for the medicine, such and such a pill at such time.

Most importantly, substance using PLH are extremely motivated to take their medication.

> Interviewer: Have you looked for medical treatment?
>
> Informant: Yes, of course. I am presently in medical treatment in the hospital, in infectious diseases. Since 2004 I am taking antiretrovirals and I have my appointments regularly and my labs as well.
>
> Interviewer: Why did you decide to look for medical treatment?
>
> Informant: Because I want to live and I want to have a quality of life in spite of my messes that I have had because of drugs, I want to have a quality of life and I know that this diagnosis won’t kill me but rather it will get better with adherence and self-care.

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Discussion

This article is one of the first to present data on the experiences of substance using PLH and their providers in a developing country. Results show that substance using PLH face a number of unique barriers to accessing medical care along the treatment cascade, including a lack of knowledge of HIV and effective treatments, inconsistent efforts by HIV counselors to link them into care, and stigma and discrimination within the health care setting. Substance using PLH are discouraged from taking lifesaving cART while using alcohol and other drugs but are given few resources to help them recover from substance use problems. Providers in this study had little understanding of harm reduction principles and many still required or strongly recommended abstinence from drugs before prescribing cART in spite of current treatment recommendations. The insistence on abstinence and other negative experiences with HIV health care providers judging PLH who relapse or use drugs led many substance using PLH to experience significant depression, to stop taking their cART when they were using alcohol or drugs, or to avoid honest conversations with providers about their continuing struggles with drug and alcohol abuse.

Results from this study show that one of the biggest barriers to linking substance using PLH to care is that HIV counselors often fail to educate them about the existence of effective treatment for HIV. In addition, few participants reported knowing anything about treatment for HIV before becoming diagnosed. This may discourage alcohol and other drug users from seeking an HIV test as they may see no benefit in knowing that they are infected with a disease for which no effective treatments exist. Outreach and prevention efforts targeting substance users may help address this problem, as the two participants who regularly sought testing were gay sex-exchangers who reported having received HIV prevention information from community organizations in the past. In El Salvador, prevention efforts have increasingly been focused on vulnerable populations with high rates of HIV, such as men who have sex with men, commercial sex workers, and transgender women. However, NIDUs have not been a target of prevention thus far, in spite of evidence that crack users have HIV prevalence rates equal to that of other populations targeted for prevention efforts in El Salvador (Dickson-Gomez et al., 2013). With increasing evidence that timely treatment of HIV with cART can prevent further infections, all behavioral interventions to prevent HIV should include information about cART and their benefits in terms of prolonging life and protecting sexual partners from HIV infection. Thus, in addition to increasing condom use, HIV prevention interventions could address the still prevalent belief that HIV is a death sentence. By doing this, such interventions may also increase the likelihood that substance users will an HIV test.

Results also demonstrate deficits in pre- and post-test HIV counseling in informing participants of the importance of seeking medical treatment and the benefits of HIV medications. Most participants reported receiving no information upon learning their diagnosis. These participants reported falling into depression, increasing their substance use and delaying treatment. However, the two women who were informed of treatment options and given appointments to see a psychologist reported no such delays in treatment, suggesting that increasing linkage to care efforts are worthwhile and likely to be effective,

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particularly as these women also reported knowing nothing about effective treatments for HIV prior to testing positive.

Substance using PLH and HIV medical providers recognized the need for more drug treatment resources. Each government HIV clinic in El Salvador is staffed by a multi-disciplinary team including psychologists and social workers. However, all medical personnel interviewed, including the psychologists and social workers, reported a lack of training in dealing with substance use. Psychologists and social workers reported trying to set up Alcoholics Anonymous meetings which were poorly attended, or individualized therapy using a 12-step approach. Members of the multi-disciplinary team could be provided training to broaden their understanding of and treatment options for substance use by training them in motivational interviewing, cognitive behavioral therapy, the likelihood of relapse, and harm reduction drug management versus abstinence only approaches. Alternatively, substance abuse treatment specialists could be contracted by the Ministry of Health to provide substance abuse treatment within HIV clinics, as some research has suggested that such interventions are most effective when provided in a single location (Meyer et al., 2013). Many providers also expressed their frustration at the lack of appropriate drug treatment centers to send their patients, particularly those who were living on the street or estranged from family. They reported that many of the existing centers would not accept PLH, or maintain the confidentiality of PLHs' serostatus. In addition, others saw significant limitations in existing centers, most of which are faith-based and depend on residents' work to support the center. As some providers pointed out, ambulatory selling exposes PLH in recovery to alcohol and other drugs and the money they earn also gives them access.

As seen in other studies, some HIV medical providers expressed very stigmatizing attitudes about substance users including beliefs that they were weak and did not want to get better. For example, rather than look for additional ways to engage alcohol and other drug users after attempts at organizing Alcoholics Anonymous groups failed, many providers concluded that the patients' had failed because they did not wish to get better. Other providers described substance using PLH as "infantile" with "defects in character" that made treating them futile as they would not be adherent. In addition, almost all providers insisted on abstinence citing the harms of mixing ART and alcohol or other illegal drugs, in spite of current prescribing recommendations from the WHO and Centers for Disease Control and Prevention in the United States. These beliefs carried many negative consequences. While some PLH talked about being diagnosed with HIV and wanting to care for their health as the impetus to become abstinent, others failed to do so because they could not find the resources to help them achieve abstinence. Negative attitudes toward substance use also had adverse effects on the patient–provider relationship, with many PLH deciding not to talk to medical providers about their substance use because of previous negative experiences. A few participants reported avoiding medical treatment because of their negative experiences with providers, whereas others delayed re-initiation of cART after a treatment lapse because of relapse. Avoidance based on experiences of stigmatizing attitudes is a common reaction to stigma. Other participants avoided family and loved ones, and still others may have internalized stigma, reporting periods of deep depression. Research has shown that positive patient–provider relationships can improve cART adherence among PLH, whereas negative

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relationships can have negative effects of treatment adherence. The responses of the PLH in this study make clear some of the reasons that poor patient–provider relationships lead to poor treatment adherence and outcomes.

Results indicate that providers should also be made aware of non-problematic alcohol and other drug use. Providers' warnings about the dangers of taking cART with drugs and alcohol also decreased medication adherence as many participants reported taking treatment vacations when using drugs or alcohol, even when their substance use was relatively minor, such as drinking beer at a party. In fact, most of the suboptimal adherence reported by participants was not because patients were not able to or forgot to take their medications. Rather, in most cases, participants purposefully chose to suspend taking cART during times when they drank or took drugs. The exception to this rule was when participants described periods of serious relapse, often accompanied by severe depression. Some participants ignored providers' advice to avoid drug and alcohol use while on cART and were able to achieve good adherence. These participants reported using strategies to remember to take their medications such as cell phone alarms, taking medications during meals or having family members remind them. Thus, much of the suboptimal adherence in this sample was a direct result of providers' advice and attitudes which are contrary to current treatment recommendations by the WHO, U.S. Centers for Disease Control, and others.

Results from this study have many implications for interventions both to improve the health of PLH who use drugs and to prevent further spread of HIV, as PLH without viral suppression are much more likely to infect others. As mentioned, interventions targeted for substance users are needed that include information about the benefits of HIV medications as well as sexual risk reduction strategies. In addition, information about cART should be provided by HIV testing counselors to all who test. In addition, for those who test positive, linkage to care efforts should be standardized and include compassionate advice and referrals to psychologists. Within HIV clinics, all PLH should be screened for problematic drug and alcohol use. Interventions, both within HIV clinics and quality in-patient drug treatment, are needed for those who screen as having problematic substance abuse. Such interventions should include options for those who are not willing to abstain from alcohol or other drug use, such as harm reduction strategies to manage substance use so it does not interfere with adherence to cART. Interventions with HIV medical providers are also urgently needed. Providers should be educated about current treatment recommendations to start PLH who meet their country's cluster of differentiation 4 (CD4) criteria on cART without regard to their substance use. In addition, the recommendation to suspend cART if PLH are going to use alcohol and other drugs should be stopped. Results also suggest that providers are in need of interventions to educate them about substance abuse to provide support to substance using PLH and to reduce stigmatizing attitudes toward substance users. Finally, as in most middle- and low-income countries, there is an urgent need for more mental health and substance abuse treatment services and better integration of these services with HIV care. Mental illness and substance abuse disorders are on the rise in developing countries and are associated with many health and social problems. Treatment for these disorders should not be seen as a luxury that none but high-income countries can afford. In the case of PLH, the potential loss of life and harm to the public health due to substance use and its inadequate management are apparent.

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Biographies

Julia Dickson-Gomez, PhD, is a medical anthropologist who studies HIV prevention among drug users in the United States and El Salvador. Dr. Dickson-Gomez's work also explores macro- and micro-social contexts of crack use and HIV risk in communities in El Salvador. Her work develops and evaluates the impact of structural and multi-level interventions in the U.S. and Latin America.

Gloria Bodnar, Lcda., is a clinical psychologist who is the director of research at the Fundación Antidrogas de El Salvador. Her research includes the prevalence of substance use in El Salvador, HIV risk of drug users, and evaluation of HIV and substance use prevention programs.

Andrew Petroll, MD, is an infectious disease specialist with a focus on the care of HIV-positive patients. His research interests include how patients' risk behaviors for HIV transmission are addressed in clinical settings, how patient-physician interactions affect the disclosure and discussion of HIV risk behaviors, and how patient and physician characteristics influence such discussions.

Laura Glasman, PhD, is a clinical psychologist whose research explores the motivational and cognitive antecedents of HIV behavior change in different contexts and among diverse populations. Her research also examines strategies that can increase participation in HIV prevention interventions, especially among Hispanic minorities and in populations where HIV is highly stigmatized.

Kali Johnson is a third year medical student at the Medical College of Wisconsin focusing on women's reproductive health. She has worked in bilingual reproductive health and

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