

FINAL REPORT

**Investigating How to Change Systems of HIV Care to Support
Smoking Cessation**

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INVESTIGATING HOW TO CHANGE SYSTEMS OF HIV CARE TO SUPPORT SMOKING CESSATION

Background:

PLWH/A have a high cigarette smoking prevalence that is well-documented in national samples and associated with many adverse health outcomes, but little is known about how to tailor cessation interventions for PLWH/A. In Oregon, the tobacco burden is high among clients in our AIDS Drug Assistance Program (ADAP), known locally as CAREAssist. CAREAssist provides nearly 3,000 low-income PLWH/A financial assistance with health insurance coverage, co-pays, and prescription drugs. The CAREAssist Program has been tracking smoking prevalence and quit behaviors among its client population since 2006; at that time, survey data showed that 42% of CAREAssist clients were current smokers, compared to 19% in the Oregon population overall. Although smoking prevalence was high, 72% wanted to quit and 83% reported interest in using medications to stop smoking if they were available at no cost. In 2008, the CAREAssist Program recognized an opportunity to integrate cessation pharmacotherapy into its drug formulary, making it available at no cost to clients whose insurance plans would not pay for them, and began providing full coverage for counseling through the Oregon Tobacco Quit Line. The program informed clients and providers of these free services, but the smoking prevalence has remained high. Survey data from 2009 indicated that smokers were still smoking and still wanted to quit, but few had used the free cessation services available. Analyses of 2009 data did not identify any client characteristics that were significantly associated with past-year quit attempts or use of free cessation pharmacotherapy. This indicated a need for research to better understand the barriers to PLWH/A using free cessation pharmacotherapy and counseling.

CAREAssist clients comprise an ideal study population because they are part of an integrated system of care for PLWH/A in Oregon that can (and will) be modified based on project findings. The CAREAssist Program is administratively linked with the Ryan White HIV case management system in Oregon. It is also closely aligned with the AIDS Education and Training Center (AETC) for medical providers and other programs that deliver services to PLWH/A. In addition, CAREAssist is housed in the Oregon Health Authority, facilitating natural, ongoing partnerships with other tobacco control resources like the Oregon Tobacco Quit Line.

Study Goal & Aims:

The overall goal of this research study was to improve understanding of the barriers to CAREAssist clients using free cessation pharmacotherapy and counseling services, in order to inform the development of an intervention that would integrate additional cessation support into the HIV system of care. We hypothesized that client, provider, and system-level barriers are preventing CAREAssist clients from utilizing free cessation counseling, receiving free cessation pharmacotherapy, and taking the pharmacotherapy as directed.

The aims of this formative study were to:

1. Describe current HIV medical provider and HIV case manager knowledge, attitude, and practices regarding tobacco cessation.
2. Describe client-level barriers to utilizing cessation services, taking pharmacotherapies, and successfully quitting smoking.
3. Describe HIV medical provider, HIV case manager, and system-level barriers to screening for smoking behaviors among PLWH/A, providing cessation counseling and referrals, prescribing cessation pharmacotherapies, and integrating these pharmacotherapies into HIV treatment regimens.

Methods:

In this qualitative study, we conducted in-depth, open-ended interviews and focus groups with HIV case managers and HIV medical providers, and in-depth, open-ended interviews with CAREAssist clients.

We selected HIV case managers and HIV medical providers for participation using maximum variation within three strata corresponding with the three Ryan White CARE Act grant-funded service delivery hubs: 1) Portland metro area (Part A), 2) HIV Alliance Service Area (Part B), and 3) All Other (Part B). In addition, sampling characteristics for medical providers included practice size, medical specialty, and health system characteristics.

Recruitment procedures for HIV case managers and HIV medical providers were as follows. Each sampled participant received an introductory letter that briefly described the interview. The project interviewer attempted to reach potential participants by telephone four days after mailing the letter, and made a minimum of 10 attempts to reach participants by phone or e-mail over three weeks. We conducted all interviews by phone, although in-person options were offered, where feasible. We conducted focus groups at providers' worksites at times convenient for them, offering refreshments, when appropriate. Medical providers received a \$5 Starbuck's card in their introductory letter as a non-contingent incentive; case managers did not receive an incentive. All participants signed a written informed consent.

We randomly selected potential CAREAssist client interview participants from among the 338 smokers who completed the 2009 CAREAssist survey and reported wanting to quit. We categorized participants into four strata: 1) clients who are interested in quitting, but had no past-year quit attempts; 2) clients with past-year quit attempts who did not use prescribed pharmacotherapies; 3) clients with past-year quit attempts who used prescribed pharmacotherapies in the past year; and 4) clients who had quit smoking in the past 1-4 years. We aimed to recruit up to 15 clients into the first three strata and 10 clients into the fourth, but ended when we reached saturation.

Recruitment procedures for clients were as follows: The project interviewer sent selected clients an introductory letter that briefly described the interview and included a \$2 bill as a thank you for considering participation; she followed up by phone four days after mailing the letter. Study staff made a minimum of 15 call attempts over three different weeks (including at least three weekday, three weeknight, and three weekend calls). The interviewer screened for eligibility over the phone to determine if potential participants were in any of the four strata. The interviewer obtained informed consent, conducted the interview by phone, and provided a \$25 gift certificate to participants as a thank you for their time. With permission, we tape-recorded and transcribed verbatim all interviews.

Results:

In 2012, we conducted in-depth, open-ended individual interviews and 4 focus groups with 53 HIV providers; in 2013, we conducted in-depth interviews that included both closed-ended and open-ended items with 50 CAREAssist clients. The final sample of 103 key informants included:

- 17 medical providers,
- 34 case managers/clinic staff, including nurse case managers, psychosocial care coordinators, and members of the HIV care team like medical assistants, and
- 50 CAREAssist clients, including 42 who were current smokers and 8 who had successfully quit within 1-4 years. Among current smokers, we interviewed 12 clients who had no past-year quit attempts (Strata 1) and 30 who had past-year quit attempts (Stratas 2 &3).¹

¹ We found few differences between clients in Strata 2 and 3, and found it difficult to clearly categorize some clients into one strata or the other because of multiple past-year quit attempts (some with and some without prescribed cessation medicine) or primary use of Wellbutrin for depression, with secondary intentions related to cessation. Therefore, we report on clients in Stratas 2 and 3 as a combined group.

We organized key findings by the grant's three original study aims, along with a fourth aim that we added after preliminary analysis of study data. Findings include key themes derived from the data, along with representative quotes from key informants. Key informant quotes, provided in italics, illustrate the theme and allow key informants a greater "voice" in the reporting, but are not meant to be representative. Quotes are labeled with participant numbers and types (CM=case manager, MP = medical provider, Client = client, FG = Focus Group, with number) to demonstrate resonance of themes across the sample.

Themes derived from the client data were consistent across Stratas 1-3, unless otherwise indicated. Clients in Strata 4 (former smokers who had quit 1-4 years ago) answered different questions, which mostly focused on their success stories. We occasionally provide a frequency count of the proportion of clients who responded to certain close-ended items in this study; these data are based on either all 50 clients interviewed or the subset of current smokers, as indicated. These data provide us formative information on issues like clients' perceptions of cessation messaging, but we will need to validate them with other samples.

In some cases, we reference quantitative data from the 2009 CAREAssist survey, in order to provide context. We mailed that survey to all CAREAssist clients; about 750 CAREAssist clients participated in the survey (60% of program enrollment at that time).

Aim 1. Describe HIV medical provider and HIV case managers' attitudes, knowledge, and practices regarding tobacco cessation.

Perhaps predictably, providers seem to view tobacco cessation from their particular professional paradigm, and approach the topic with their clients accordingly. Although all providers recognize both the psychosocial and medical aspects of tobacco use and cessation, HIV case managers generally focused on psychological issues and behavioral supports, whereas HIV medical providers spoke more frequently about addressing cessation as part of chronic disease management, usually by employing pharmacotherapy and/or NRT.

HIV Medical Providers' & Case Managers' Beliefs and Attitudes about Cessation:

Both HIV medical providers and case managers believe that smoking cessation is important and say that helping clients quit fits within their respective scopes of practice. Many providers mentioned that preventive health issues generally, and smoking cessation in particular, have become a more important part of HIV care in the post-ART era.

"That is very high on my list of things I do: trying to help the clients with their physical health. And smoking cessation is one of the top things that I want to address if they do smoke." (CM 103)

“I’m certainly very interested in getting people to stop smoking, especially at this stage of the HIV epidemic, where people are living a long normal life and we can focus on things like that.” (MP 202)

“I think it should be a very high priority in providing comprehensive care for HIV because with well-controlled HIV, high CD4 count, undetectable viral load, those folks are not going to be impacted by their HIV, but they very well may be impacted by their tobacco use.” (MP 205)

“Well, I tell people if they can keep their bodies healthy, it really helps with the HIV. So, I’m all about anything to keep them healthier: nutrition, smoking cessation. You know, it’s a big part of it because probably something else will get them besides the HIV.” (FG2)

However, both types of providers noted that smoking cessation and other types of health promotion are still secondary in importance to ensuring appropriate HIV medical treatment for clients. For case managers, this means a focus on supporting clients’ initial entry and ongoing engagement in medical care, as well as addressing deficits in basic needs that might prevent clients from achieving HIV treatment success.

“Our mandate is to get people into medical care and keep them in medical care and to maximize their adherence, if that is applicable. Under that is everything that somebody would need to have a stable and non-chaotic life, in order to participate in medical care and take their prescriptions ... and all of that.” (CM 108)

“I’m not saying [cessation is] not a main concern. It is, but just addressing taking your medications, having something to eat, having a place to stay, that comes up a little bit more.” (CM 109)

HIV medical providers noted that while they need to address a spectrum of important issues as part of comprehensive HIV care, including tobacco use and cessation, HIV adherence is always their highest priority. If a patient does not have well-controlled HIV disease or presents with adherence problems, smoking cessation will pale in importance.

“In an HIV practice, frankly, the adherence piece should take precedence. You know, in terms of prioritizing that golden hour that one has with somebody.” (FG1)

“I don’t know how to rate [smoking cessation]. I guess on a scale of 1-10, it’s probably a 7. It’s not quite as important to us as actually taking the medications.” (MP 207)

“I know as part of our medical system, when they vital the patient, they do ask a smoking question and document it. That’s a routine part of our taking the vitals. Whether we have time or ability to address it in detail in a clinic visit really depends on how severe their other issues are. You know, with stable HIV, without other medical problems, who’re doing just fine on the meds, those are the ones I have the luxury to have some extra time to really in detail hit these issues. So every patient is not the same.” (MP 206)

HIV Provider Knowledge about Cessation Resources:

When asked about cessation resources available to clients, HIV case managers focused on behavioral supports (or the lack thereof) and medical providers generally focused on cessation medications. Provider knowledge about the two main resources that CAREAssist clients can tap for cessation help—the Oregon Tobacco Quit Line and free pharmacotherapies through the CAREAssist Program—varied among and between both groups. Case managers and most medical providers knew about the Quit Line, although many medical providers were not clear about the services the Quit Line could provide to smokers.

Provider Knowledge of & Experience with the Oregon Tobacco Quit Line:

HIV case managers readily identified the Oregon Tobacco Quit Line as a resource they offer to clients, whereas medical providers demonstrated a wider range of knowledge of and experience with the Quit Line. Although many medical providers said they refer patients to the Quit Line, most appeared to have only a vague understanding of the services they provide. A few had never heard of the Quit Line.

“I do make a point in my exam rooms of keeping the Oregon Quit Line brochures, the 800 number, and making sure I give that to every patient, so they have access to that counseling, the phone counseling thing. I always type up smoking cessation information in our after-visit summaries. It’s this pre-printed thing we can give to the patient, so I try and give them those extra motivators and tips to follow through. I think the Oregon Quit Line is the main external offer.” (MP 206)

“We give them the Oregon Quit Line information and all that sort of stuff.” (MP 209)

“I think I’ve heard of [the Oregon Tobacco Quit Line], but it’s not something I’m really familiar with. I haven’t ever requested my patient to call it... I guess this Oregon Quit Line is interesting. I didn’t know about that and that I could refer my patients there. So that’ll be interesting for me to look into more.” (MP 208)

“I think it’s curious. I’ve never called the Quit Line myself, but I’d like to know what they do. Do they offer specific advice?” (FG4)

Provider Knowledge of & Experience with Resources Provided through CAREAssist:

Although all of the providers seemed very familiar with the CAREAssist Program, most case managers and medical providers were confused about what cessation services were available through the program.

“I don’t know if CAREAssist even covers... would it cover the cost of the nicotine gum or patches? I’m not even sure.” (CM 103)

“I guess I’m not even sure if CAREAssist is still paying for [smoking cessation resources].” (CM 107)

“I think there is a disconnect with that piece from CAREAssist because I don’t know that everybody out there knows that if you have [insurance] coverage and it doesn’t cover [cessation resources], that CAREAssist would pick up [the cost].” (1st provider) ... “Actually, I didn’t know that until right now (2nd provider).” (laughter). (FG1)

How Oregon Providers Address Cessation with Clients:

Very few medical providers and no case managers used language consistent with the 5As for tobacco cessation², although many appear to be performing some of the 5A functions. Providers approach cessation very differently, depending on their professional training and role. HIV case managers said that they take a “holistic” and “client-centered” approach that lets the client determine when, how much, or even whether smoking cessation will be addressed. Medical providers, on the other hand, said they took a more directive approach with patients.

² The 5As are: ask about tobacco use, advise smokers to quit, assess willingness to quit, assist with quitting, and arrange for follow-up.

Structured Approach to Cessation:

Nearly all providers—both case managers and medical providers—said they do not use a structured approach to addressing cessation with clients who smoke. However, most described some existing supports that help them address smoking cessation with clients on a routine basis.

Case Managers: Annual Assessments and Carefully Chosen Advice

Case managers frequently mentioned the annual assessment as a time when they always ask about smoking; client need and case manager discretion determined when or if other interactions about smoking cessation occurred at that time or during subsequent encounters.

“One of the questions on our assessments is to ask them if they smoke cigarettes. So, right up front, I can get that information from them. Generally, then, I go through all the papers for the assessment. I gather lots of information and then at the very end I will tell them that on my care plan, I would like to make that one of the problems on my care plan, the cigarette smoking... I think we have that added into our assessment because we believed that it was important to know. I don’t know. Do we have a protocol set in place for us to follow to assist clients? Not really. I just have the flyers.” (CM 103)

“No, [I don’t have a structured approach to addressing cessation], at least not that I’m aware of. It’s in my head, but not on paper.” (CM 104)

“[Smoking cessation] is part of our annual screening. All of the clients I serve get an annual triage with me, and we do screen for whether they are smoking and what their stage is for talking about quitting—whether they are contemplating, actively want to quit, need a referral for the Quit Line, or want smoking cessation devices.” (CM 107)

Many case managers talked about the line they need to walk between advocating for health promotion-related behavior change with clients and ensuring that clients feel supported, and not judged. Case managers said that conversations about smoking generally are client-driven, and that they use motivational interviewing techniques to determine how to best approach the topic with clients.

“Smoking cessation is one of the top things that I want to address if they do smoke. But I have to ask them if [smoking cessation] is something that they want me to address with them, or talk about... I still need to be in a position that I want them to call me, and to know that I’m not going to be judgmental of their behavior. I want them to know

that I accept them for whatever they want to do. I sort of have to follow their lead.” (CM 103)

“I do the motivational interviewing and harm reduction. So, what would make you stop? I use those techniques, and then I leave it up to them. And then reassess later on to see why it didn’t work. That is usually how I address it: what are your barriers? And maybe if you are smoking 20 [cigarettes], let’s go down to 18, and then go from there... because cold turkey sometimes doesn’t work.” (CM 105)

“I discuss with them the risks of smoking... It’s not my prime role to see that they stop smoking, but it’s part of the whole package to help them stay as healthy as they can... I would say all of my clients are complex, with multiple health needs, so I don’t want to badger them about anything in particular. I have to be very careful that I don’t turn them off and they don’t think that I am riding them or criticizing them or something. But I’m there when they are ready.” (CM 112)

Medical Providers: Ask, Advise, and Take Advantage of Teachable Moments

Although none of the HIV medical providers specifically referred to the “5As,” many of their responses embodied 5A concepts. Medical providers varied in their approach to smoking cessation, depending on their specialty (e.g., primary care vs. infectious disease specialist) and the health system in which they worked. Some medical providers described working in a comprehensive system that addresses tobacco use with the client at multiple points. Others described a more situational approach to discussing cessation with clients, which includes questions at an initial visit which they may or may not revisit in a routine way during subsequent encounters. Most providers, however, said they ask clients known to be smokers about their current smoking and advise them to quit at every visit.

“We advise smoking cessation at every single visit. We have our staff who first inquire about smoking before the physician comes in, then they advise ways to quit smoking and offer Quit Line [information], and then the physician also emphasizes it. And for our scope of practice, we can offer other modalities that staff cannot, like medications. So it is very much a part of our practice and we are just going to start having our on-site pharmacist who is connected to our clinic also do smoking cessation counseling. So we’re heavy on it.” (MP 210)

“On every single encounter, I always assess for smoking status. I always assess for alcohol intake and drug use. A lot of my patients are social drinkers and smokers. So, it’s important for me to know because that constantly changes. So, every single encounter I have with the patient, first, as part of the vitals is to inquire if they are smoking or not. And if they are, then I provide them with smoking cessation counseling at different

levels. I can start them on simple interventions, prescribe the patch or nicotine gum, to full work-ups and prescribe stronger medications, if needed... Every single encounter I have with my HIV patients includes smoking cessation.” (MP 204)

“I guess I ask them if they’ve tried to quit before and if they had, or what they’ve used before, and if they were successful with that. Depending on how they’ve done it before and if they’ve had success, I might have them do the same thing.” (MP 209)

“I’m a general practice family doctor, and I see lots of different kinds of patients. And everyone over 18, we ascertain their smoking status, and advise them to stop smoking if they are smoking. And we have a process that we go through for helping them to do that. I certainly use that with people who are living with HIV also.” (MP 202)

One medical provider reported using motivational interviewing with smokers, but most providers reported using practices that match the ‘AAR’ model³, a briefer version of the ‘5As.’ Specifically they ask about smoking, advise patients to quit, and refer them to resources. Some said they try to relate cessation advice to other medical problems or simply fit cessation into “*the general flow of care,*” in order to make the conversation feel more natural.

“I ... just insert it into the general flow of care. We don’t have time to do a 15 minute behavioral motivational interviewing technique, but we do have time to say ‘hey, are you still smoking? Are you interested in quitting? Well, try to cut down by a quarter of a pack by the next visit’ or whatever. That takes 20 seconds.” (FG1)

“I integrate it as a medical issue, they have blood pressure, they have HIV, they have depression, they have tobacco abuse and then, depending on the time we have and the relative acuity of the other issues, I treat it as a problem on the problem list with a plan and start meds to get rid of it.” (MP 206)

“I’ve found that people respond really well, particularly if we are talking about starting on a cholesterol medication. I’m like ‘listen, we can treat this number up here on your screen, this LDL, but if you are still smoking there is something so much more important that we can be trying to figure out. So let’s start this medicine while we are working on

³ The Centers for Disease Control lists the AAR model as an alternative to the 5As. The model was initially piloted by the American Dental Hygienists’ Association as the ‘Ask, Advise, Refer Initiative.’ It modifies the 5As by emphasizing only 3 steps: 1) ask about tobacco use, 2) advise the patient to quit, and 3) refer the patient to a quit line for telephone counseling in support of cessation.

that.’ I think people respond to that, as well. Ok, you are worried enough about my health, my heart disease risk, but you want me to start this whole new medication for cholesterol, oh, and smoking is a bigger risk— maybe there is a bigger risk to this.” (FG1)

Some medical providers said that they reinforce cessation messages during teachable moments when patients might be more receptive to the standard messages providers deliver over and over.

“You pick your moments... now, it’s much more about bringing it up, making sure it’s on the table, and reminding folks occasionally, and then when they get sick—particularly with anything respiratory—say: ‘Hey, you’ve already cut back to three cigarettes a day because you can’t smoke without wheezing and getting short of breath, so maybe now’s the time to go no higher than that at least. Or maybe you want to start some medication now to help you get off of them completely.” (FG4)

“Whenever patients come in with upper respiratory infections or colds or pneumonia, especially in the winter...I often give a little reminder at those visits, ‘you really should quit smoking to help you get over this cold quicker and also quit smoking for your health, in general, for the long run.’ And, you know, the more respiratory tests and the more they come in for respiratory problems, the more it rings a bell in terms of ‘yeah, I’ve really got to deal with this.” (MP 206)

Aim 2: Describe client-level barriers to utilizing cessation services, taking cessation pharmacotherapies, and successfully quitting smoking.

Client Attitudes about Cessation and Desire to Quit:

Among the 36 current smokers⁴ we interviewed in 2013, 31 said they were seriously planning to quit within the next six months.

Clients generally summed up their attitudes about smoking cessation clearly and succinctly:

“If I could get a handle on the smoking, I would be really happy.” (Client 192)

⁴ Six clients in our sample were not smoking at the time of the interview, but had quit less than 1 year prior, so did not meet our definition of ‘former smoker.’ Thus, quit intention data were only gathered for 36 subjects.

"I really want to quit...Smoking is my biggest problem. If I can beat that one, I will be OK." (Client 347)

However, clients and providers said that some clients develop a "defeatist" attitude after trying multiple products and tactics without achieving or maintaining a successful quit attempt:

"People say: 'well, I've tried everything and I can't quit.'" (FG1)

"[I have] kind of a defeatist attitude. You know, you try this and you try that and then you think, 'well, I seem to go all over the globe, so to speak, with acupuncture, and Chantix and hypnosis.' You know, you get a defeatist attitude, which, of course, is the wrong attitude...it's like sheesh. I really, really, really need to quit. I need to get a grip on this." (Client 140)

"Yes, I know I need to stop, but there is nothing I can do about it at this time." (Client 287)

"Smoking is so insidious with us... you can't ask people 'why aren't you going to group? Why are you throwing in the towel so quickly?' You can't ask that because there could be reasons you can't even imagine, but it seems that they give up, it's too hard. [They think], 'this isn't going to work.' I think many smokers have that kind of attitude going against their favor." (Client 124)

Client Motivators to Quit:

Clients and providers identified health and finances as the leading client motivators for cessation. Other motivating factors identified by far fewer key informants included family, negative impacts on appearance, and smoking bans in apartments, hospitals, or correctional facilities.

- Motivation to Quit: Health

Like nearly all smokers, CAREAssist clients know that smoking is bad for them, and they likely have a heightened sensitivity to health concerns because of their HIV disease. However, key informants indicated that while a general awareness of negative health ramifications may move HIV+ smokers into contemplation of quitting, it often takes negative health consequences to move clients into the preparation or action stages of change:

“The more they come in for respiratory problems, the more it rings a bell in terms of ‘yeah, I really got to deal with this.’ Patients who have a little health scare, it motivates them more.” (MP 206)

“I was smoking and I felt like I was going to come down with pneumonia. I felt some discomfort in my chest—not unlike [similar] discomfort from a couple of years ago when I did get pneumonia. And it was smoking related. And I was like, ‘no, I can’t let that happen again’...getting those chest pains said to me, ‘you could be about to get pneumonia again, if you don’t stop.’” (Client 124)

“I’ve been giving it thought because of how hard [smoking] has been on me. By 6:00 at night, I am in a lot of pain, real pain that the medications don’t stop, and I can hardly breathe and it’s probably a lot to do with the cancer, but also because it is so aggravated by the smoking.” (Client 235)

“This time when I quit, to tell you the truth, it really wasn’t a big problem. I didn’t fret over it. I was so sick and tired of smoking and I knew it was harming my lungs and I could feel it cutting down my breath when I was walking and exercising and I said ‘that’s it’ and I put [my cigarettes] up, put them on top of the refrigerator and just quit, cold turkey. I didn’t go through withdrawal or anything. I just had my fill of cigarettes; I’m not going to destroy my body anymore. I haven’t had even a puff of a cigarette since.” (Client 284)

- Motivation to Quit: Finances

All three types of key informants discussed the deleterious effect of an expensive habit like smoking on low-income CAREAssist clients. HIV case managers and medical providers were acutely aware of—and often frustrated by—the financial difficulties faced by clients who smoke:

“It’s amazing to me how many of my clients are living below the poverty level, and yet they manage to continue to smoke...of the small amount of resources they have, they will devote a fairly significant portion of it to smoking.” (CM 104)

“I cannot tell you how many people I’ve had in one office or another, so upset about their financial situation, absolutely pissing and moaning about how broke they are and how it’s really terrible for their lives. And I think cigarettes are like \$5 a pack, and they find that money, whatever they have to do for it.” (CM 108)

“These days, I would say cost [is a motivator]. It keeps going up for cigarettes. I do have patients coming in saying, ‘I can’t afford it anymore. It’s too expensive. I want to quit.’

The higher the price goes, the more patients sometimes get motivated, which is a good thing, I think.” (MP 206)

Likewise, many clients recognized that quitting smoking would benefit them financially; some were motivated enough by the prospect of economic gain and improved quality of life to quit:

“[When I was smoking], I knew it was bad for me if I was or wasn’t HIV positive. But it was just the money—every 3 days, it was like \$17, so that added up to about \$300 every month [that I was spending on cigarettes]. I just don’t have that to spend on something so frivolous.” (Client 170)

“It’s five bucks a pack and if you smoke a pack a day, that’s \$150; when you’re on a limited income, that’s a lot of money... that’s 10% of my income every month.” (Client 289)

“I spend about \$120-\$150 a month on [cigarettes]. So I need to really buckle down and get back on the wagon because I just invested in a vehicle and I’m on a limited income and there are lots things wrong with the car.” (Client 292)

However, a number of clients echoed the providers’ observations that smokers will always find a way to pay for tobacco:

“When I was a serious smoker, I didn’t care how much it costs me.” (Client 302)

“I know it sounds crazy, but you budget for [smoking]. As a smoker, you budget for it. So you’re not really thinking about what you can save as opposed to, ‘Oh my gosh, I have to have this much money for my next pack of cigarettes.’ It’s a whole psychological thing that you always have money for cigarettes, even if it’s change from your drawer.... There’s no logic involved in lighting a cigarette. Does that make sense?” (Client 382)

Client Context for Smoking/Smoking Behaviors:

Overall, CAREAssist clients are older (median age of program participants=46 years), and smokers in this study reported long-term tobacco dependence. The median age of clients in this study was 52 years, and the median age of smoking initiation was 18 years old. Among the 42 current smokers, 2 of 3 reported smoking every day and the median number of daily cigarettes was just under a pack (n=16).

Why Clients Smoke:

Both clients and providers identified two key reasons why clients smoke. Smoking among CAREAssist clients was most commonly associated with emotional regulation and mental health issues: the two main themes that emerged were stress and loneliness/isolation.

- Stress: Smoking as Self-Medication

Both clients and providers frequently said that clients smoke as a way to deal with stress. Clients spoke in general terms about the “*calming effect*” of a cigarette when feeling anxious, and provided many specific examples of life stressors that may have foiled a quit attempt or prevented them from initiating one. Some examples included the death of a friend, a work crisis, putting a dog to sleep, and an unexpected change in housing.

“I do have a lot going on and sometimes it just stresses me out. I am a high stress person and that keeps me smoking, I think.” (Client 332)

“The calming of a cigarette works for me. Pain is a trigger for smoking along with a letter from Social Security, you know, when you have to deal with paperwork and all that, and you’re not sure how to fill it out, you get really nervous and uptight.” (Client 287)

“Actually, both my partner and I got some patches, oh, early summer, and we were really thinking about the quitting thing before this other [thing] happened... And we had actually quit for a while, and it seemed like this stressful thing came along and then bang, there we were again.” (Client 114)

Case managers and medical providers tended to speak more broadly about clients’ use of smoking to deal with larger mental health and trauma histories.

“[Many clients have] really huge, overwhelming trauma histories, and, you know, the ongoing residue with that. They have difficulty with emotional regulation and want to self medicate. I’d smoke, too...” (CM 108)

“They are often self-medicating with tobacco, and I tell them that there are healthier ways to self-medicate that won’t have the fatal side effects of tobacco... I think that [stabilizing clients’ mental health] would go a long way towards mitigating the smoking: less stress, and less anxiety and depression.” (CM 112)

“The smoking tends to go with other psychiatric issues. Then they feel like it’s the one thing they can’t quite let go of yet while they’re dealing with their other stresses.” (MP 208)

- Loneliness: Smoking as a Companion

Clients identified social isolation and loneliness as a contributor to smoking. Some clients said that cigarettes fill a void in their lives, and are like a “companion” or a “friend.”

“You said earlier that a high rate of HIV positive people smoke and immediately I thought: it’s our little alone conversation, [it’s the] mechanics of the thing. You smoke and bring it up and exhale...It’s a companion... maybe you just got back from labs with your doctor and things are improving, but not improving, and you don’t have anyone to share with and you go smoke like Betty Davis did in the movies and you think and exhale and you have another drag, and it’s like having a companion, a talking companion.” (Client 110)

“I am way more successful on quitting and staying quit if I can be in a positive place with myself and busy doing something... we’ve got friends and we talk about this. ‘Why did you start smoking again?’ ‘I don’t know, I just don’t have anything to do and I’m lonely and it just feels good.’ I have a friend who says that. And I understand it; I see it completely.” (Client 114)

“I spend too much time home alone, by myself, in my own patterns.” (Client 115)

“I tend to isolate in my house and I’m alone, bored, and smoking kind of becomes a friend, as it were.” (Client 124)

Case managers reiterated the importance of social isolation and noted that it has a larger impact on continued smoking than belonging to social networks of smokers, as we had initially hypothesized.

“They just might be going back to their four walls where they are isolated and lonely, and mental health problems set in, and a cigarette helps that.” (CM 101)

“I would say a lot of my folks are isolated, and it’s not so much that they are affected by their peers as that they are lonely.” (CM 112)

Client History of Cessation, Including Experiences with NRT and Pharmacotherapies

Most CAREAssist clients in this study said they tried to quit many times, using a variety of cessation methods. The median number of lifetime quit attempts was five, although responses ranged from “never” to “every day.” The following are a few typical responses to the question, “How many times in your lifetime have you tried to quit smoking?”

“I can’t really remember, but probably seriously at least 20.” (Client 108)

“Oh, four... no, five times.” (Client 166)

“Oh, God, lots...a dozen.” (Client 300)

Most of the current smokers we interviewed had tried a variety of smoking cessation methods in their lifetimes. We asked about their experiences with nine different cessation methods, ranging from “cold turkey” to Chantix. About 1 in 6 clients had tried only one method, 38% had tried 2-4 methods, and 45% had tried 5 or more methods. Cold turkey was the most common method (88%), followed by nicotine replacement patches (60%), Chantix (57%), nicotine replacement gum (52%), and Wellbutrin (45%).

Use of behavioral supports was less frequent. Twenty-nine percent reported using the Quit Line and about 1 in 5 had used individual or group counseling or cessation classes.

About 15% of current smokers reported never having used a nicotine replacement product or pharmacotherapy in order to help them quit smoking. Among these “cessation treatment naïve” clients, none had used the Quit Line. Among these six clients, three said they had not used any products because they felt they could quit on their own, two were concerned about side effects or medication interactions, and one was interested in pharmacotherapy, but didn’t know if his insurance would pay for it.

Experiences with NRT, Including Patches and Gum:

Many clients who had used patches (9 of 25) viewed them as effective and easy to use:

“You can tell that [the patches] are working...It works, and helps with the urge to smoke.” (Client 155)

“I didn’t need to [keep smoking] with the patch. It took that craving away, more so than the gum did.” (Client 192)

“After the first couple of weeks, I wasn’t even thinking about [smoking] anymore, so those patches worked pretty well.” (Client 242)

"I figured I would try the patch and it worked. It works for me...the minute I put the patch on, then I don't smoke." (Client 300)

However, six patch users said the patches did not reduce their cravings for nicotine or "*didn't work fast enough*" to be an effective smoking cessation tool. All but one of these clients smoked while using the patch. We do not have data about dosage, so were unable to evaluate whether providers prescribed appropriately and/or whether clients used the products correctly.

Ten clients who used patches reported a side effect, most commonly skin problems. A few reported sleep disturbances, including insomnia and/or "*weird dreams*," and one person mentioned feeling dizzy and nauseous. Some people considered the side effects to be serious enough to discontinue using the patch, while others considered them more of a nuisance. Surprisingly few said their experiences would prevent them from trying patches again.

"[I used the patch] a couple of years ago. It would just kind of itch and burn...I thought I would just get used to it." (Client 109)

"[The patch] gave me a rash. I couldn't do it...I put it on one arm and a few days later I had a rash. Then I changed to the other arm and I got a rash on that one also. After two weeks, I was through." (Client 312)

"The patch, it didn't seem to affect me very much except my skin got highly irritated and bubbly, from wherever I put the patch...The skin would just start falling apart. It would just eat the skin. It almost looked like psoriasis. It was burning and wounds and all that stuff...I would try again. You know, it's possible that I used them incorrectly, or didn't follow through and use them long enough. So, trust, me, [I'd try] probably anything." (Client 140)

Twenty-two clients reported using nicotine replacement gum to stop smoking, either alone or in combination with the patch. The most common comment about gum, shared by 8 of the 22 gum users, was that it tasted bad. Two users said they experienced side effects from the gum; one developed mouth sores and the other experienced an upset stomach. Others found the gum inoffensive and two reported liking it, but none of the clients seemed overly impressed with its effectiveness.

Some clients were confused about how to properly use patches and gum, or were uncertain about how NRT should work. Additional education about combination therapy or how to manage cravings would have been beneficial to many of the clients:

“When I started to get to the lower [dose] patches, I started smoking again...They come in three stages and when I was at the last stage, I started smoking a little bit. It wasn’t long before I lost the patch.” (Client 108)

“Yes, [I used the patch as prescribed]. Well, no, probably no. Because what I would do is I would wear the patch, and then I’d pop the gum whenever the craving got real crazy or too much, so I would kind of double dose that way. Yeah. And in that way, I wasn’t really addressing the habit part of it...because I was popping in a piece of gum.” (Client 114)

Experiences with Pharmacotherapies, Including Wellbutrin and Chantix:

About half of current smokers had used other pharmacotherapies besides NRT, to try to stop smoking; 19 reported using Wellbutrin and 24 had used Chantix.

Consistent with the literature, clients were much more likely to report success with Chantix than Wellbutrin:

“Wellbutrin had no effect whatsoever...it was like taking a jelly bean: nothing.” (Client 287)

“Chantix just worked. I don’t know why; it was like a miraculous thing. I didn’t feel like smoking cigarettes anymore. I didn’t have that sensation anymore.” (Client 109)

“I got to preaching to people about Chantix...it’s all right. I mean, I slowly, but sure[ly], slowly but sure[ly], slowly but...and it was all gone and I really didn’t need [to smoke].” (Client 121)

However, a majority of people who took Chantix (20 of 24) and/or Wellbutrin (13 of 19) reported side effects. The most commonly cited side effects for Wellbutrin included sleep disturbances (e.g., insomnia, bad dreams), anxiety, depression, and seizures. The reported side effects from Chantix were predominantly psychological, including depression, suicidal thoughts, anger, and irritability. A few Chantix users reported milder symptoms and two said they enjoyed the dreams they experienced. In general, however, clients reported more severe side effects from Chantix compared to Wellbutrin, and many discontinued taking Chantix because of the side effects.

“The side effects with Chantix were like deep depression and suicidal thoughts and everything. I went through a real hard, like a downward depression, so I eventually quit taking Chantix after about two weeks...I think the Chantix helped me, but I just couldn’t deal with the depression.” (Client 160)

“Chantix made me really, uh, psychotic feeling...It changed me. It wasn’t good...It helped me quit, but it was making me flip out.” (Client 431)

“It was difficult to sleep...Chantix made me very agitated and irritable. I wasn’t smoking while I was on it, but apparently it made me a not very nice person.” (Client 322)

Client Access to NRT and Pharmacotherapies:

Providers frequently identified the cost of pharmacotherapy and NRT as a barrier to clients using those cessation products and successfully quitting, even though they are available for free. Clients who used NRT and other pharmacotherapies however, overwhelmingly reported that accessing them was easy and involved little or no cost to them. Here is a sample of typical client responses:

“My insurance paid for [Wellbutrin, and then Chantix]. It was easy.” (Client 109)

“The Chantix? My insurance covered a portion of it and my CAREAssist paid the rest.” (Client 129)

“They prescribed and paid for [the patches], so I guess CAREAssist paid for them, because I didn’t.” (Client 242)

“It was paid for, the whole thing. I just took the prescription to the pharmacy; it’s in the same building as my doctor and I just picked [the patches] up.” (Client 262)

“I think they paid for [Chantix]; I can’t remember... Yeah, it was easy; very easy.” (Client 292)

“[Getting the Chantix] was easy, of course. My insurance paid for it and I just simply picked up the prescription from the pharmacy.” (Client 294)

“The doctor wrote the prescription. I took it to the pharmacy and it was all paid for.” (Client 302)

“Yeah, she just wrote me a prescription [for Chantix] and, in fact, the insurance covered it... It was pretty easy; the pharmacy took care of all the paperwork for me. And they

were really helpful; they gave me the pamphlets and all the literature to read about it. The pharmacist told me about the three minute rule and how to distract yourself when you really, really want one. It was helpful.” (Client 327)

“[Getting the prescriptions filled and paid for] was all taken care of through CAREAssist.” (Client 357)

Only one client reported difficulty accessing Chantix in about 2008 or 2009. The client reported that a month passed before he was able to get the prescription filled. However, the client still felt it was worth the effort because he was able to successfully quit (although later relapsed).

“[It was] hard [getting my prescription]...It required going back to, let’s see, how did that happen? The drug was refused by the insurance company and so it had to go back to—oh, the doctor went to fight for it and she got some sort of a person, there is a person that works for her that does nothing but that kind of thing, so that person was able to get the Chantix, but, of course, I had to join [the Oregon Tobacco Quit Line], but she got it for me. It took like over a month though...Well, it didn’t matter. To quit was good.” (Client 235)

Does Existing Medication Burden Limit Adherence to Cessation Medications?

We hypothesized that existing medication burdens from ART and other chronic conditions might create a barrier to PLWH choosing cessation pharmacotherapies and taking them as directed. However, only one client in our sample expressed disinterest in cessation medications, including NRT, because of his existing medication regimen:

“For me, that just wasn’t an option, given I take nine different medications and so, the last thing [I’d do] would be adding a tenth one to it.” (Client 189)

Providers also did not identify medication burden as a barrier to clients choosing cessation pharmacotherapy:

“It’s mostly getting them to the point of considering [pharmacotherapy] and once they’re there, they’re already on so many other medications that it’s not so much of an issue, I think.” (MP 208)

Client Attitudes about the Oregon Tobacco Quit Line:

CAREAssist clients have had access to four free counseling calls through the Oregon Tobacco Quit Line since 2008. In the 2009 CAREAssist survey, 12% of clients who identified as current smokers had called the Quit Line since 2008. Most clients interviewed for the current study reported that they had never used that service. The most common reason clients gave for not

using the Quit Line was the belief that they didn't need the Quit Line because they could quit on their own.

- Quit Line: I Don't Need It

Some clients said they believed they didn't need the Quit Line because they had successfully changed other habits on their own; others indicated that they generally disliked asking for help.

"Because I don't think I need to rely on others. I quit hard drugs seven years ago; I don't go to meetings or anything. I just don't need a crutch." (Client 126)

"Well, I just figured that I would do it on my own. I don't usually like to have emails, or people calling me asking me how I'm doing." (Client 172)

"I didn't think I needed to. There have been other things I had to quit and I just did it. But this smoking thing is different." (Client 245)

"I just figured if I really wanted to [quit], I would just do it." (Client 199)

"[I didn't call] because I'm a man...We don't need help. (laughter)." (Client 305)

- Quit Line: I Don't Know About It

The second most common reason clients gave for not calling the Quit Line was that they didn't know about it or were unclear about what services the Quit Line could provide.

"I'm not even sure what [the Quit Line] is." (Client 140)

"I didn't even know there was an Oregon Tobacco Quit Line." (Client 166)

"I just really don't know a lot about it...Yeah, I've heard of it, but I really haven't checked into it much." (Client 108)

"I don't have any reasons. I think I have been aware of that number." (Client 155)

Client Barriers to Successfully Quitting

Clients and providers identified several key barriers to CAREAssist clients quitting smoking and staying quit. These included competing needs, tobacco addiction, and lack of social support.

Barriers to Quitting: Competing Needs:

Providers, in particular, said that clients often have so many competing needs that smoking cessation is triaged down in importance. Competing needs generally fell into four sub-categories: basic needs, drug & alcohol issues, mental health and other physical health issues.

- Basic Needs: Smoking is the Least of My Worries

Providers said that many clients come to them in crisis mode because they have immediate basic needs to address, like housing, food, and transportation. CAREAssist clients, by definition, are low income, so many are struggling with the consequences and correlates of poverty.

“Health promotion is probably a lower need than shelter, food, and medical care. And when those things are stable, then I think [smoking cessation] tends to become somewhat of a high priority.” (CM 102)

“I think a lot of my case load is people that are just chronically struggling. With the economy right now, financially they are struggling. I’m not going to tell somebody ‘you need to quit smoking just so you can go buy food.’ Their lives are stressful. I have people that are going in and out of housing and being homeless. I’m not going to tell them to quit smoking. Their anxiety levels are high enough the way it is.” (CM 103)

“The other thing is, if we work on their basic needs: food, a place to live, and they have basic things met, and then we can address this. For a lot of them, it’s like ‘I have to smoke because I have so many problems.’ For you to bring it up, they just look at you like... So, [we] address the basic needs first.” (CM 105)

“With our population, it seems like so many folks are like barely housed, barely have enough food, barely have enough clothes, barely have a way to get to the doctor, and all of that sort of takes precedence.” (FG1)

- Drug & Alcohol Use: “Smoking is My Last Vice”

Current and former substance abuse is prevalent among PLWH. Many providers said they take a harm reduction approach to smoking cessation, choosing to address any current abuse of drugs and alcohol before addressing tobacco.

“A lot of my clients have major alcohol and drug issues. So, maybe the smoking piece at this point in their life is not the priority.” (CM 111)

“Where I bump into problems is with the competing needs... Sometimes there are competing addiction issues, where tobacco is the least of what I’m worried about.” (FG1)

Clients and providers also said that many clients see smoking as their “last vice.” Clients have given up other habits—whether by choice or necessity—and aren’t ready to give up the last vestiges of their former identities.

“Smoking is their last thing. It’s their last vice and their last addiction. I think there’s a lot of fear that if they give that up, everything else they’ve done is going to come crashing down because they can’t manage to keep everything together if they give up that one last vice.” (FG3)

“Getting clean and sober, a lot of times, with that comes ‘well, I have to give up everything else, and I’m not giving up smoking at this point.’ (CM 111)

“When people are dealing with chronic illness like HIV, they have to give up a lot of things...Cigarettes tend to be a crutch and they can’t see that giving that up will improve their lives. It’s something they just don’t want to give up because they’ve had to give up a lot of other things, and that’s the only thing left.” (FG4)

“It’s about the only vice I have left. I’m kind of reluctant to give it up.” (Client 327)

- Mental Health Issues: “We All Smoke”

As with active drug and alcohol issues, providers said that mental health issues must be addressed before approaching tobacco cessation. Both providers and clients acknowledged that smoking is a common way to cope with mental health issues like depression and anxiety—so much so that smoking among people with mental health issues is normalized.

“Bipolar, depression and anxiety... Sometimes, people that are in the midst of struggling with those things, I don’t even try to say quit smoking. It’s almost like they have to have their personal life in a good place before they are going to be able to tackle that.” (CM 103)

“Coping with many things including depression would also help me stop [smoking].” (Client 155)

“Well, you know, I think that there is only so much that we can do...Perhaps if they had access to mental health providers to break the cycle of depression, to break the cycle of mental disease, perhaps it can break the cycle of smoking, as well.” (MP 205)

“Yeah, I have a diagnosis of bipolar type 2 disorder and when you are mentally ill, it’s almost like you’re in this club and everyone in this club smokes, and I’m being a little facetious, but there is some truth in it, ‘cause I used to think that way. If I stopped for a period, I was like, ‘why did I stop? I’m mentally ill. We all smoke.’” (Client 124)

- Physical Health: “You Have to Prioritize the Health Issues”

According to the 2009 CAREAssist client survey, 4 in 5 CAREAssist clients have at least one other serious chronic condition, in addition to HIV. For some clients, managing their HIV disease and any other chronic illnesses is all that the clients—and sometimes their providers—feel they can handle at one time, even though, paradoxically, quitting smoking would likely improve all of their health conditions.

“I think this kind of falls off the table...the most prevailing need [gets addressed]: they are losing weight, they are not taking their meds, they don’t have current scripts. The tobacco ends up being more of a secondary concern. I think the hope among everybody is that you try to get them stabilized, and then you can go back and pick up those secondary concerns when they are in a better place. But that doesn’t happen very often. Crisis prevails more often than not.” (CM 106)

“[I’m not going to try to quit smoking] within the next six months. We just now got my HIV under control. I changed my treatment to [a new doctor]. We are working on that right now.” (Client 392)

“You have to prioritize all of their health issues. So in a super sick patient with not well-treated HIV who’s also diabetic and this and that, you’re working very hard at every visit to get their meds under control, to get their diseases under control, you know, a little bit more elective issue like smoking cessation falls to the lower priority list. And in some patients, you never quite get to it. (MP 206)

- Competing Needs: “It Becomes Overwhelming”

Although most of the identified competing needs are not HIV-specific, PLWH experience many of them concurrently, which can complicate cessation efforts. The sheer number and complexity of issues that must be addressed can become overwhelming to clients—and sometimes to providers, as well.

“My clients typically are having a lot of other struggles... they have a lot of other barriers in their life, so in their mind, [smoking is] something that is the least dangerous to them, or the least high on their list of things to worry about.” (CM 107)

"I almost get the feeling that the underlying sentiment would be 'I have HIV and that is life threatening and that's enough for me to deal with. I'm not going to deal with what smoking might do to me.' You know, smoking is minimized in the face of the other stuff that they seem to be dealing with, and the emotional reaction to that stuff." (CM 110)

"It becomes overwhelming. [The clients think] 'I have to take my medications, and I have to stop this, and I have already stopped this and this, I just don't want to do one more thing.' So that could be another barrier, where 'I've done too much and this is all I can do for my health right now.'" (CM 102)

Tobacco Addiction:

Both clients and providers noted that the most obvious barrier to quitting is that tobacco is an addictive substance, and clients have generally been addicted for a long time. Like any addiction, breaking free from tobacco takes time, energy and environmental supports that CAREAssist clients may not have available. In addition, many clients who have had addictions to other substances say tobacco has proven to be the hardest to overcome.

"You know, I know that I need to quit. I know it's bad for my health. I mean, I'm not stupid... You know, it is an addiction and there's not a whole lot more that I can say. It's just a horribly, nasty addiction. Pretty much, I've been smoking since I've been in the womb." (Client 194)

"I would think the barriers are the same as anybody who is trying to quit smoking. It's the addiction of the tobacco. I feel like being an ex-smoker, I can stress that it takes time, and a change of lifestyle, not being around someone who smokes, and both of you in the house have to quit at the same time." (CM 103)

"If I had a day or two of success at not smoking, for that short of time, most likely the main reason I took it up again was the addiction... I have occasional urges to smoke and then I have to go through a little history mentally... remembering that in the past when I did that, I would again be caught, addicted to cigarettes." (Client 124)

"It's always on my mind to quit; I just can't seem to do it. I'll tell you it was easier to stop alcohol and drugs than it is my cigarettes." (Client 262)

"I think [smoking cessation] would ideally be part of a comprehensive approach to addictions in general. That would be probably the most successful way to get at it." (MP 209)

Lack of Social Support:

Many clients and providers identified a need for social support during a quit attempt. Clients who did have support reported that it helped them to quit.

“It was mostly that I had decided to quit [that I was successful], but it was really good to have other people rooting for me.” (Client 219)

“Everyone was really happy and supportive. Both my parents smoked when I was young, but they quit really early on and so they were like very happy and supportive for me.... [My partner quit] three or four months before I did... That helps. Yeah, definitely to have someone there to be supportive of me and to kind of help me along, I guess. That definitely helps.” (Client 160)

“I was in church at the time and I did pretty good, but one way or another I started smoking again. The church really helped me.” (Client 347)

However, many clients are socially isolated and do not have a personal support system of family and friends. This is especially unfortunate because as one provider (MP 202) said: *“It’s possible that [PLWH] might need extra support because smoking is associated with anxiety and depression, which a lot of them have.”*

“Most of the clients that I’ve seen in the case management program don’t have very much in the way of social support.” (CM 102)

“My support group was away, the email and all the people that never let me down that were so happy to see that I had quit smoking and everything...but since I retired and moved out to the country, I think it was just easier to smoke because I didn’t have to feel guilty about anybody saying anything to me. And I think that is probably why I started again. I don’t know.” (Client 235)

“I only have one family member that I really talk to and to be honest, I don’t have any friends, just neighbors that are kind of like friends. To be honest, I don’t really have that many friends.” (Client 289)

“Hmm, [I would have been more successful] probably if someone close, a partner or someone was there and encouraging, without being alone.” (Client 110)

Smokers in Social Networks:

Some clients talked about living with or being around smokers as a barrier to quitting. Triggers included a partner who smoked during a quit attempt, groups of people smoking in front of smoke-free housing, and support group participants who smoke in the parking lot on breaks.

However, an equal number of clients said that because they had indoor home smoking bans, having a housemate who smoked had “*no effect*” on them. Others said they were successfully able to avoid smokers during their quit attempts because of the greater number of smoke-free environments in Oregon, including bars, and because they now knew fewer people who smoked.

CAREAssist Client Advice: Get Support:

Some CAREAssist clients who successfully quit recommended that other CAREAssist clients seek support to help them through their cessation attempt, and some clients who had not sought support in the past and were still smoking said they planned to get support during their next quit attempt.

“If they are serious about wanting to quit, my suggestion is get somebody to talk to. I think that would have been a good thing for me, too, [when I was quitting].” (Client 277)

“Well, this time [when I quit] I’m going to go for a lot of supports— support groups, you know?” (Client 292)

“I would say [to CAREAssist clients who want to quit] that whatever it is that you think will help you [quit], then do it. If you need friends to help you, then get your friends. If you have a partner who wants you to quit, use that.” (Client 219)

“I do have a plan [for my next quit attempt]. I’m finally going to have some type of support system and somebody is going to help me make a plan, because I know when those types of stressors come up, [I need a] deep breath or whatever it takes.” (Client 382)

Aim 3. Describe HIV medical provider, HIV case manager, and system-level barriers to screening for smoking behaviors among PLWH/A, providing cessation counseling and referrals, prescribing cessation pharmacotherapies, and integrating these pharmacotherapies into HIV treatment regimens.

Providers identified one leading barrier to helping clients quit smoking, and several minor ones. The key barrier identified by both HIV medical providers and case managers was a lack of time for screening, counseling and referrals. Providers also identified some concerns about resource availability.

Providers Lack Time:

Both HIV case managers and HIV medical providers consistently said that they lack the time it takes to thoroughly address smoking cessation. Providers said they felt pinched by the number of clients they need to see in a day and the wide range of complicated issues they need to address. Many feel frustrated that they can't focus more on health promotion issues, including smoking cessation.

"The health promotion things don't get the same level of focus, because you just don't have enough time." (CM 102)

"But the reality is—and I don't want to say we don't have time—but we don't have time. It would be great if we could take more of that [health promotion] role, I think that would be our intent anyway. It is hard to add more. I don't know about other case managers, but I assume it's the same. I am buried." (CM 110)

"Time management is hard. I mean, I'd love to spend more time on health basics, but it just doesn't always work out that way." (CM 111)

"I think that the biggest barrier would be time, because of the patient load I have, the population I have and manage. Time constraints would not allow me to do more." (MP 204)

"This is a terrible confession, but we now have a button in our system, which I do check almost every time, which is substance abuse. And it will say tobacco, and I have two questions: 'are you ready to quit?' and 'have you sought counseling?' And it's almost like 'don't say yes, don't say yes. I don't have time today.' Because then I have to do my whole spiel and we have to talk and I have to write a prescription. Just say 'no, I'm not ready to quit.' Ok, good. I mean, not good! But we'll talk about it at another time. It's terrible." (FG1)

"We have a million other things we need to talk about with them." (FG4)

- Integrating Smoking Cessation into Antiretroviral Therapy (ART) Adherence Counseling:

We asked providers whether it would be useful and potentially time-saving to integrate adherence counseling for cessation medications into adherence counseling for ART, since clients generally take multiple medications and ART adherence counseling is such a prominent part of medical management for HIV. In general, providers did not understand how such an approach would work or felt that it would be too cumbersome.

“I think it sounds wonderful [to integrate smoking cessation with adherence counseling]. Again, with time constraints and practical issues, I’m not sure if it’s possible...We don’t have a dedicated pharmacist or dedicated counselor specifically for HIV who could do more targeted counseling, particularly regarding HIV; it’s just me and the case worker.” (MP 201)

“I’d be interested in hearing about it... how that would work...It makes sense to deal with those things together, but I don’t really feel like I have the tools to be able to understand that right now unless I got some education about it.” (MP 209)

“I feel like that would just be a lot to add to at least a first adherence type visit. Even at a follow-up visit, sometimes it’s talking about different potential [ART] regimens and those can sometimes still be a ton of information for somebody.” (FG1)

One provider thought that adherence to cessation medications was not an issue for clients.

“When patients are ready to stop smoking, they very much adhere. They finally got the Chantix or they have their patches, and they want to use them. I think it’s actually one of the easiest things to get them to adhere to because they finally made the decision. It’s not like you are saying, ‘OK, you need to start taking this for your high blood pressure or your high cholesterol, and they are like ugh.’ This is something they finally want to do for themselves, so they commit to it more easily than for any other therapy.” (FG4)

Lack of Knowledge about Resources:

Providers reflected a general awareness of the types of resources that are available to clients, but lacked details about sources of payment or specific benefits. Medical providers said they share information about NRT, pharmacotherapies, and the Quit Line with clients, and clients generally agreed that they received this information on a regular basis from providers. However, medical providers, in particular, expressed confusion about what specific services the Quit Line provides.

Need for Behavioral Supports: Classes & Groups:

Many case managers and some medical providers identified a need for more behavioral support services to help clients through the quitting process, such as cessation classes or groups. However, many simultaneously expressed skepticism that clients would utilize those resources, even if they were available.

“Many of our clients are not in tune to attending classes or support groups. But some people do ask if there is something that they can participate in that will help them [quit smoking]. If something like that would be available on a local level, at least to try, that might be something that would be helpful... [but] continuing education isn’t something that they do, so as much as I think that it might be beneficial, it may flop.” (CM 102)

“I guess I wish they had more...some of our clients don’t have families to support them. So, I don’t know. There’s not a quit smoking support group anywhere. That’s one of the things you don’t see. There’s a support group for everything else, but not that.” (FG2)

“We’ve got social support groups for people with other issues, but not for tobacco.” (MP 208)

“I think the chronic disease management model might be a better model than a group. Groups are just so hard. They don’t like to come in.” (FG4)

Need for Behavioral Supports: Individual-Level Support:

Providers also indicated that individual-level behavioral supports, like counseling or coaching, would be helpful, but said few sources for individual-level support are available, except for the Quit Line.

“I’ve had a lot of clients quit for a while after using a series of the patches or Chantix. Unfortunately, not a lot of them have remained off the cigarettes. So, I think it’s probably a matter of them really needing a lot of coaching while they are getting the series of patches, like using them correctly and not smoking while you are using them or getting the weaning process correctly.” (CM 107)

The CAREAssist program provides access to up to four free Quit Line coaching calls as part of its smoking cessation benefit, but few clients report using the Quit Line. Consistent with client data, several providers said that clients do not seem to use the Quit Line, even though most providers are aware of its availability and make referrals to it:

“I can only recall one person actively using that line. They are more focused on getting the patch, or the gum, or Chantix or something, not necessarily using the Quit Line.” (CM 107)

“They are not real gung ho about [the Quit Line]...I’m not getting a lot of takers on the Quit Line. When I give out the card they kind of look at me like, yeah, whatever.” (CM 110)

Some providers shared ideas for other types of individualized support or coaching beyond the Quit Line that might be helpful.

“If you said, we have a specialty nurse and her focus is on smoking cessation, and we did it in like a chronic disease model where it’s like ‘here’s our plan, here’s your quit date. You’re going to meet with a nurse, and the nurse is going to sit down with you and talk about those things.’ Then maybe they might engage one or two times, but then they could talk by phone, and see which interventions are working. It’s kind of difficult to meet weekly for a group when they have so many other things to do, appointments, and things. But if they had one person to engage with that they could meet with right away, then that might make the difference.” (FG 4)

“I wonder if a more appropriate target [for client cessation counseling]...might be the mental health/substance abuse counselor.” (FG1)

Others felt that the real system barrier was larger and that the gap that needed to be addressed was the lack of overall mental health and addiction services or the need to have better integration of behavioral health services with HIV medical care, issues that may be addressed by changes in the health care system as part of the Affordable Care Act:

“I think if there were more resources for mental health and addiction, [then] that would help with smoking cessation, and would also help with medication adherence and HIV care in general because so many HIV positive people have those other diagnoses. You know, if I had mental health [resources], if it was within the walls of my office space, so that I could send somebody down the hall to the psychiatrist who’d be available to help out, or somebody down the hall that I could ask a question of during a visit with a patient, if there was integration [of] mental health and HIV practice, I think that would be very helpful.” (MP 205)

“What would really work is if there was a complete overhaul of basically everything, and there were enough services that their lives could become calmer and they could more effectively engage in mental health services, and maybe over time reduce the need to self medicate and be able to get the skills to quit smoking...” (CM 108)

“[Smoking cessation is] a behavior change, so it takes a lot more staff support basically. And I think that is what has been coming up. Who is following up, and that type of piece. So from a systems standpoint, it is having more support.” (FG1)

Barriers to Accessing Resources—Is Payment for Multiple Quit Attempts Blocked?

As reported earlier, clients who accessed NRT or pharmacotherapies overwhelmingly reported that they were easy to obtain and that the cost was covered. One person reported a problem accessing the Quit Line:

“I had tried it and I had an appointment arranged to confer, because they had got me on my cell phone when I was not in a situation to answer it, and we set up a time and I waited around all day and so I got miffed and I called, and they said, ‘Well, you’re on the schedule. We’re supposed to call you,’ and then I just got indignant after that and felt I had wasted my time.” (Client 110)

Several medical providers and case managers reported that they knew of clients whose insurance had denied payment of NRT and other pharmacotherapies if a client had tried them unsuccessfully, and then initiated a subsequent quit attempt.

“I have had a couple of clients who have reported ‘it was only covered once, and if you don’t quit that time, then you can’t get back on it.’ And I didn’t know if that was true or not, but I have had that reported to me by one client twice and a couple of other clients once. They said ‘I tried that and I didn’t successfully quit or I started again, and I can’t afford it now because it’s not covered more than once.’” (CM 110)

“They will call the Quit Line and not everything is available, or maybe this is their third time and their insurance company isn’t going to pay for another round of nicotine patches, or whatever.” (FG1)

“I think they are limited, though, as to how many times they can [access cessation resources], and that’s something that needs to be taken into account. I think people need to try to quit multiple times, and the system does not allow for that.” (FG4)

It is difficult to know how common this phenomenon is, since no clients reported this experience, but clearly this would be a system barrier to any client who experienced it. The CAREAssist Program has not imposed payment restrictions related to multiple quit attempts. If a client’s insurance carrier restricted payment for subsequent quit attempts, CAREAssist would cover the charge, but clients and providers may be unaware of this benefit or could simply consider the extra steps too burdensome.

Policies and Systems that Positively Impact Cessation Screening and Counseling:

Medical providers and case managers mentioned two systems that support their efforts to provide cessation screening and counseling: electronic reminders and the inclusion of tobacco use on annual assessment forms.

The Electronic Medical Record: Tobacco Use as a Vital Sign:

Several providers mentioned that they found it useful to have a place in the electronic medical record system to note tobacco use as a problem, to have periodic reminders to follow up with the patient, and to make notations on patient handouts related to smoking cessation advice.

“I’ve tried to make some interventions using the electronic record and trying to make sure [tobacco use disorder] ends up on people’s problem list... it reminds me every time to ask them about it, even if they are there for ... other issues. Also, they can see their problem list, so they can see that I have listed that as a diagnosis...And I’ve made a dot phrase [in our EMR], so I’ll actually talk to people more than just asking them about it.” (FG1)

“Within my clinic system, we have an electronic medical record that I can make a chart note.” (CM 107)

“In our [EMR] system, we have a place that asks ‘are you a current smoker? A former smoker?’ And usually when they do the additional assessment, there’s a place for how long you’ve been smoking and how much you smoke. And then you can go in there and hit update. And then there’s also several diagnosis codes related to smoking. I think the main one is tobacco abuse...And then we have a problem list. We use the problem list a lot, so that will show up there as an issue. So it comes up when we are looking at it or if we send it to someone else.” (FG4)

Similarly, case managers mentioned that having tobacco use as part of the annual assessment was helpful, as it ensured that case managers and clients have that discussion at least once a year:

“It is part of the basic assessment, part of the health assessment piece, which I think we are required to document in CAREWare if I’m not mistaken. So that’s an annual, at least an annual, process with every client. If they are going to be on our caseload, we have to do a health assessment and tobacco and other substance use is part of that health assessment. (CM 106)

A few case managers, however, noted that because tobacco use is not part of the acuity scale that their system uses to triage clients, smoking cessation gets deprioritized compared to issues that are included in the scale.

“There is an acuity evaluation for substance use, and ... tobacco use doesn’t even fall into that... I think we are really missing something by not having that as part of their acuity [score], because that is a huge area where they have the control, or at least the power to improve their own health.” (CM 102)

“I think it’s a matter of role definition, prioritization, and we are told that our big [issues], what we are supposed to focus on is that people are adherent to their medications, health and nutrition, they are taking care of their liver, and they are taking care of their dental health. Now, if smoking were added as one of those priorities, that would be something...Smoking is not one of them yet.” (CM 112)

Client Barriers Perceived to Outweigh System Barriers:

Many key informants said that the main barrier is client readiness to listen to cessation messaging and to access the available resources, rather than a system barrier.

“It’s really frustrating that there are a lot of resources being brought to bear for this population but their addiction and dependence issues are so in the forefront that they can’t always effectively utilize the resources.” (CM 106)

“I’d say those [client-level] things [are barriers], nothing structural, I think we have a lot of support structurally to help people quit.” (CM 107)

“It’s not an issue of ‘oh, I can’t pay for patches,’ it’s ‘I need my nicotine.’ (CM 112)

“I don’t see any other barrier other than their own personal, emotional readiness.” (MP 203)

Aim 4: Develop messaging to move clients along the stages of change to a place where they can use existing resources to make an effective quit attempt.

Developing educational or promotional messaging for clients was not among our initial study aims, but we added it after preliminary analysis of our study data, when it became clear that such messaging is needed. We identified two issues to address through well-targeted health communications: a lack of awareness of CAREAssist program resources related to tobacco cessation (for both clients and providers) and a lack of readiness among smokers to access resources.

Awareness of CAREAssist Program Resources:

About half of the current smokers we interviewed for this study (20 of 42, 48%) reported that they did not know that CAREAssist provided smoking cessation resources. In addition, as described earlier, many providers seemed unclear about the specific resources to which they could refer clients. Because of a huge increase in program enrollment since 2008 and many important program changes, CAREAssist program staff lacked time to promote the smoking cessation benefits to clients and providers as much as was needed. We can help the program address this gap.

Client Stage of Change:

Many clients and providers indicated that the primary barriers to clients quitting was that clients were not ready to access available resources; they needed to move into a further stage of readiness before being able to successfully utilize cessation resources. According to 2009 CAREAssist client survey data, 72% of CAREAssist clients who smoke want to quit. However, clients and providers both said that unless clients are really prepared to quit—that is, unless they are in the ‘action’ stage of change—neither provider advice nor a wealth of resources will be enough.

“I think it really has a lot to do about your mindset; whether you are ready to quit or not.” (Client 108)

“The main barrier is getting to the point of truly wanting to quit versus just saying they kinda want to quit, but not really being motivated. It’s the degree of motivation...Figuring out ways to motivate patients is always the crux of the issue.” (MP 206)

“I believe that you can have all the tools in the world, [but] if you’re not ready to quit it’s not going to work. You have to be mentally ready to quit. You have to be done with it and mentally ready to do it.” (Client 300)

Providers spoke about the need to use motivational interviewing or other types of behavioral counseling to help clients move along the stages of change to a place where they can successfully tackle the challenge of quitting smoking, and to tailor their interactions with clients based on their current stage of change.

“There is the sequence of being ready to change, so I deal with that. If they really want to change, I’ll throw everything at them. If they say, well, someday I want to change, but I don’t want to now, I’ll say ‘ok, it’s here for you when you are ready for that one.’” (CM 112)

“And like every other addiction, the person has to be ready, and you have to introduce the idea along the classic stages of change because people are in and out, they’re on and off. They are interested and then not...At the point that you are prescribing, they are in the driver’s seat as far as being the one who wants to do it, because I am not going to prescribe otherwise. I’m not one of those doctors who say: ‘You need to quit smoking. Here’s a pill. Good luck.’ That’s a waste.” (FG4)

“My take on it is that if someone is not ready to quit smoking, they will always have an excuse not to do it. So you know, part of my talk is not only to look into quitting smoking, but to try to assess on whether they are ready to quit smoking or not.” (MP 204)

No Magic Bullet:

Key informants contrasted true readiness with an attitude that pharmacotherapy is a “magic bullet” that will quickly eliminate a problem that developed, for most, over a lifetime.

“I feel like probably in 50% of the situations the patient is like “wow, I can just use Chantix or the patches and I’ll quit.” But, really, they haven’t done the mental piece of “yeah, I’m really ready to quit.” So it’s like this is going to be the magic bullet that is going to help me quit. It’s an unrealistic expectation, I think, so they are not really even thinking of the Quit Line as another tool they have. They just want the quick fix.” (CM 107)

“I’ve gotten to a point where I’m not going to quit again unless I decide to quit for good.” (Client 114)

“I felt that something had turned inside of me and I was just ready to, I was just ready to commit to what I said I was going to do, which is quit smoking...You know, it just doesn’t seem like there is any sort of a magic bullet. I’m not sure why what worked for me did work for me...because it was just time to quit?” (Client 219)

Are Medical Providers the Best Messengers?

Consistent with the literature, CAREAssist clients appear to listen to health messages from their doctors’ more than similar messages delivered by others. Most clients said their doctors spoke with them regularly about smoking cessation; many said that the physician initiated conversations about smoking at every visit. Clients reported receiving cessation messaging from both primary care physicians and HIV specialists; in some cases, clients see one provider who serves as both PCP and HIV specialist.

“I would say the [conversations with my doctor] are very important to me...they keep me thinking about needing to quit.” (Client 245)

“She asks me [about smoking] every time I come in...I trust my doctor. I’ve known her for 15 years. It’s nice to know she is there and will prescribe anything I want...She wants me to quit... [She] helped me to quit [before] and she is always willing to help me quit again.” (Client 109)

“[My doctor] says at this point I need to worry more about my cigarette smoking than I do HIV. He mentioned that tobacco would probably be what kills me, before HIV would... [We have these conversations] every time I see him, about every other month [or] every three months. Yes, every time. He’s definitely big on that... I’ve had to reframe a lot of stuff.” (Client 115)

“Every time I visit my doctor, [we talk about quitting and he offers me referrals and resources]... [The conversations] are as important as breathing. They confirm that I want to quit smoking... I’ve got to quit. That’s about it; that’s the size of it. It’s one of the biggest threats to my health.” (Client 150)

“Well, yeah, [those conversations with my doctor about smoking] were important. I would rather hear it from her than from someone else.” (Client 242)

Although many health care systems take an integrated approach to health promotion, with various members of the team addressing topics like smoking cessation, clients reported that messages from their physicians carried more weight than similar messages from their HIV case managers. Some HIV case managers indicated that despite their emphasis on health promotion, clients tend to view them more as conduits for accessing financial resources, and many clients concurred with this view.

“I think that a clinician giving a strong health message that if you continue to smoke, just like if you continue to be overweight, you can look at a shortened life for all of these reasons with HIV [is the most important]. I think that would have more weight than anything I have to say. And also ... I have this weird relationship with them that is financially based, and so the health messages? I’m not sure how strong they are coming from me.” (CM 110)

“[My case manager and I] usually talk about better things than smoking.” (Client 121)

“No, [my case manager] hasn’t seen me smoke. She has no idea. She doesn’t bring it up. She’s more there to help me with things that personally I can’t handle, situations that maybe I’m struggling with. She gives me resources.” (Client 235)

“No, [my case manager and I haven’t talked about smoking]; we talk about other stuff.” (Client 245)

“[My HIV case manager] says something [about smoking], but I don’t pay much attention to her. I’d rather pay attention to my doctor anyway.” (Client 302)

“I really haven’t talked with [my case manager] about [smoking]. Never thought about asking her...She might [have brought it up]. To be honest, I never really paid attention...because [the case manager] is not in the same class as the doctor is in, so I don’t remember, as well.” (Client 327)

Still, physicians pointed out that other people in the care team can and must play a role in reinforcing the message, since physicians struggle with time constraints. HIV case managers and others on the care team can be a secondary source of messaging, and can take the lead in supporting clients in accessing resources (e.g., assisting and arranging for cessation):

“I think having many points of contact for this conversation is just key... The onus cannot always be on the physician. This is an easy enough conversation that it does not take a medical school degree to discuss this with somebody.” (MP 210)

“Any time people can hear or be offered assistance to quit, I think that would be a benefit. And it doesn’t have to be a physician, it could be a mid-level or ancillary staff, if they can integrate it into what they do also that would be helpful, yes.” (MP 201)

Messaging Clients Found Motivating:

We shared six basic cessation messages with the 42 current smokers, and asked them how much each message might motivate them to quit smoking. We developed the messages based on existing literature and cessation campaigns targeting LGBT communities and PLWH.

Consistent with the information they provided about reasons for wanting to quit, the cessation messages that resonated with the most clients related to finances and health.

About 3 in 4 clients (74%) said that they found the following message very motivating:

“If you stop smoking, you could have about \$2,000/year to spend on other things.”

“That’s really; you know, that is probably the most empowering one...For me, it is [very motivating], you know, and [add] a caption of a nice vacation somewhere. Yeah, I know what we spend.” (Client 194)

“Get out of town, no way, that much? Are you serious? Oh my God, that much? Holy cow...I didn’t even want to hear that. Oh, that irritates me. Oh, all the money I’ve spent. Good Lord, that’s very motivating.” (Client 150)

Just over half of clients (57% and 52%, respectively) found the following two messages to be very motivating:

“Smoking stresses your immune system and every part of your body. HIV-positive smokers have more serious health problems than non-smokers.”

“Now that your HIV is under control, smoking is a bigger health problem than HIV.”

“Yeah, [that’s] motivating. My doctors told me that. The chances of me dying of HIV, the virus, are pretty slim. It’s going to be something else, so yeah, I’m aware of that.” (Client 305)

“I think the new information is that it’s not HIV that’s gonna kill you. I mean, if you smoke, it’s not the HIV you have to worry about; it’s the tobacco and smoking.” (Client 110)

“Especially with a compromised immune system, it is just ridiculous to be smoking period. So yes, I would say it’s highly motivating.” (Client 140)

The other three messages appeared to resonate with fewer clients. About 4 in 10 clients (41%) found the following message to be very motivating: “Quitting smoking is the best thing you can do for your health.” Some clients said that the message seemed too simplistic or felt that the term “best” was distracting.

“I’m not one to jump on that best word, ‘it’s the best thing to do for your health,’ though. Maybe you need to lose weight; that could be a best thing, too.” (Client 110)

Only a third of clients found the two remaining messages to be very motivating (31% for each). The messages were: “You’ve worked hard to stay healthy with HIV and you can live a long, healthy life. There are resources to help you quit smoking,” and “Do you have too much going on to quit smoking now? Help is available when you are ready.”

Both messages reassured clients that cessation resources are available. However, few clients mentioned structural barriers to accessing cessation resources. Although some were unaware of the specific resources available to them, such as the Oregon Quit Line or their CAREAssist benefits, clients rarely mentioned lack of resources as a reason for not quitting smoking.

“If I need help, I can get help from every agency you have mentioned so far. You know, my doctors, my primary and my HIV doctor and my, you know, case worker, I can get all that help just by calling, if I am motivated to call.” (Client 177)

“That’s not very motivating. Basically, it is telling you there is a resource that I can get to later, so I’ll just wait.” (Client 287)

Framing the Message/Teachable Moments:

Providers offered information about what they saw as “teachable moments” or the best times to deliver cessation messages. They recognized that clients move through the stages of change, and that the steps are not always linear. There are specific times and circumstances that may make a client more receptive to cessation messages and providers try to capitalize on those:

“It’s catching people at that teachable moment, and having resources available.” (CM 102)

“We talk a lot about how patients these days don’t die of HIV, they live long, long lives and some of the major causes of death with lifelong HIV are cardiovascular, and cancers... Often, we tie their current chronic illness into quitting smoking, to help them be healthier down the road.” (MP 206)

“There are key times when you can introduce [cessation]. There are ripe moments for actually intervening... When they have an acute respiratory infection, so if they’re coming in with bronchitis, and they know that their cigarettes have a component in that, and they are already smoking less. When they raise taxes on cigarettes... that’s another time when I really work on encouraging people to quit. And then certainly, there are times when, after you set the stage for years and years, they will walk in and say: ‘I’m ready. My landlord won’t paint the walls of my apartment until we stop smoking.’” (FG4)

Positive Messaging around Health and Finances:

Although specific health promotion messages tailored to this group of smokers are yet to be developed and tested, providers and clients suggested that a positive tone may be helpful. Providers and clients said that an emphasis on the health and financial benefits that clients could accrue through quitting smoking may be more effective than stressing the negative effects of continuing to smoke.

“I try to stress the positive instead of the negative. In other words, if they would quit smoking their HIV medications will be more effective, their body will be stronger. They can taste foods. They can breathe. I try to make it a positive thing, not show them scarred lungs or anything.” (CM103)

“Well, one thing that is really motivating is when I quit for the year; I saw a little flyer on the bulletin board in the immune deficiency clinic. And it told you what happens to your body when you quit smoking, in a matter of minutes after 24 hours, after 7 days and so on and it was pretty remarkable about how your blood oxygen levels changes and how quickly you can get healthy. Now that was motivating. That was really, really motivating.” (Client 300)

“I would really tie [cessation messages] into long-term health like I do in my clinic. If you take your HIV meds, you keep your HIV under control for decades, you’re never going to die of AIDS or an opportunistic infection but you’re at higher risk for x, y, and z, and you’ve really got to be pro-active with that. I think that resonates with a certain number of patients, not all, but some. I think tying it into being healthy over a lifetime. You don’t want to be treating your HIV just to die of lung cancer at age 50. You want to be healthy over your lifetime. So [it’s important] to turn it into a positive message for lifelong health, I think.” (MP206)

“When I’ve had people who have quit, a lot of it has been based on: ‘I figured out how much money I’m smoking, and I can get a dog and care for a dog and have something [if I quit]. I can do these other things.’ (FG1)

Success Stories from CAREAssist Clients who Quit:

Finally, some of the best messaging about the benefits of quitting smoking may come from CAREAssist clients themselves. We spoke to eight former smokers who had quit in the past 1-4 years and stayed quit. They shared many of the benefits they are experiencing from being tobacco-free, including improved physical, emotional, and financial health, and greater enjoyment from food and favorite activities.

“The immense improvement in your health and the way you feel is a great reason alone to quit smoking...I found for myself that by quitting smoking, I got rid of the two to three times a year of pneumonia that I was getting, which would of course drop my [CD4] count levels. And for me, that was one of the biggest reasons; I had my HIV in complete control, yet I was still allowing cigarettes to make me ill. By quitting, I now have complete control of my health.” (Client 129)

“I’m a musician and I’m actually a pretty good singer and I consider it a miracle that I still have my voice left, so I am able to sing now, and even now my voice is improving as I move farther away from having smoked. I’m a swimmer, which I know doesn’t go hand in hand with smoking, but I can swim now for much longer during a swim session than I could when I was smoking. Food tastes better... those things go hand in hand with not smoking.” (Client 219)

“[Since I quit], I’m breathing easier; it is like I pretty much have my full breath back. I’ve had a lung x-ray and my lungs are in good shape. I go out and I still like to jog and go climbing around the hills and stuff and I am breathing so much easier and it is so much more enjoyable to go out and do those things I love to do without struggling to breathe.” (Client 284)

Additional Data Collection:

We had not originally planned to interview dental providers as part of this study, but we modified the study protocol to do so. Oral health issues are common among PLWH/A, and two dental clinics are an integral part of the HIV continuum of care, so visits to these dental providers could provide another important opportunity for tobacco cessation support. We are currently trying to reach and interview providers from the two major HIV dental practices in Oregon to gain additional data about the feasibility and acceptability of this idea among dental providers.

Disseminating Study Results:

We have disseminated results through presentations and trainings to providers in the HIV continuum of care. In April 2013, we presented study findings to HIV case managers, in conjunction with a practical skills training by a tobacco cessation specialist from Oregon Health & Science University. We also presented study findings to mixed audiences of CAREAssist clients, providers, and stakeholders at two HIV-related advisory group meetings. Study findings will be presented at additional local and national meetings, as appropriate. These will include local and State planning councils, advisory groups for Cover Oregon (Oregon’s name for

Affordable Care Act efforts), and other stakeholder groups.

We expect to submit approximately two manuscripts for publication in peer-reviewed journals. The manuscripts will address new findings that could help practitioners design effective cessation interventions for PLWH/A and potentially other low-income populations. The target journal for our initial manuscript will be *AIDS Care*, which recently published results from a related qualitative study (Robinson W, Mood-Thomas, S, Gruber D. Patient perspectives on tobacco cessation services for people living with HIV/AIDS. *AIDS Care* 2012;24:71-76).

Next Steps: Developing Interventions:

This study's results identified barriers to CAREAssist clients quitting smoking and using available free cessation support, and these barriers will help inform short-term and long-term interventions. In the short-term, we are considering a promotional campaign to providers, HIV case managers, and clients, as well as simple systems changes to reduce barriers to accessing resources. The CAREAssist Program will fund these short-term actions. The results of these short-term actions will inform the long-term actions, including possibly applying for another research or practice grant.

Short-term actions:

We are working with Oregon's tobacco program to design a promotional campaign for HIV providers, case managers, and clients. The CAREAssist Program could fund this campaign, with in-kind support from the state tobacco program. The promotional campaign will be focused on the following objectives.

Objective 1. Increase HIV medical provider prescribing of cessation pharmacotherapies and referring to the Quit Line by:

- a. Increasing their awareness of free cessation services available through CAREAssist.
- b. Increasing their awareness of best practices for cessation pharmacotherapy (e.g., combination pharmacotherapy, dosage of NRT) and what additional help PLWH/A might need regarding managing side effects.
- c. Increasing their knowledge of what the client experiences when calling the Quit Line.

- d. Increasing their motivation to prioritize tobacco cessation (e.g., if a client quits smoking, they will have more money for housing & more housing options because of smoke-free policies; also reinforce health benefits of quitting).

Objective 2. Increase HIV case managers' practice of asking, advising, and referring to the Quit Line and other cessation services, including "talking to your doctor" by:

- a. Increasing their awareness of free cessation services available through CAREAssist.
- b. Increasing their basic awareness of best practices for cessation pharmacotherapy (e.g., combination pharmacotherapy, dosage of NRT) and what additional help PLWH/A might need regarding managing side effects.
- c. Increasing their knowledge of what the client experiences when calling the Quit Line.
- d. Increasing their motivation to prioritize tobacco cessation (e.g., if a client quits smoking, they will have more money for housing & more housing options because of smoke-free policies; also reinforce health benefits of quitting).

Objective 3. Increase clients' motivation to attempt to quit and to stay quit by:

- a. Increasing their awareness of the importance of quitting for their health, looks, voice, finances, and other motivating factors using success stories from other clients interviewed.
- b. Increasing their hope that they can successfully quit using stories from other clients interviewed.

Objective 4. Increase clients' utilization of cessation pharmacotherapies & cessation services by:

- a. Increasing their awareness of free cessation services available through CAREAssist.
- b. Increasing their awareness about what can help them quit ("what works")
- c. Increasing their awareness about the importance of adhering to NRT and other pharmacotherapies, and what they can do to manage side effects.

The promotional approach for clients would aim to deliver messages to them from seven different modes (e.g., social media, mailers, CAREAssist website; posters for medical providers and case managers; HIV medical providers and case managers; feature story about a CAREAssist clients successful quit and how it helped them; other earned media) over a short period of time. To inform the campaign, we would supplement results from this study with those from the 2013 CAREAssist Client survey. That survey included questions about tobacco, cessation, media usage, and trusted sources for health information.

In addition to planning this promotional campaign, we are working with the state tobacco control program and CAREAssist to explore the possible system changes below.

Objective 5. Institute faxed referrals to the Quit Line from HIV providers and outbound calls to clients from Quit Line.

Objective 6. Coordinate with existing chronic disease self-management resources like the Positive Self Management Program (Living Well) for PLWH/A, and expanding self-management resources, where needed.

Objective 7. Coordinate with CAREAssist Program to assess the feasibility of adding tobacco use status on CAREAssist Program Enrollment and Continuing Enrollment Review forms.

Objective 8. Coordinate with Ryan White-funded HIV case management programs to assess the feasibility of adding tobacco use to the client acuity scales.

Long-term actions:

We plan to evaluate the success of these short-term actions with funding from CAREAssist, and those results will inform the need for longer-term actions that could be funded by a future research or program grant.

Long-term actions might involve system changes or cessation interventions tailored to PLWH/A. For example, we may find the need to address the problem of insufficient HIV medical appointment time for cessation counseling and referrals (e.g., the person scheduling the appointment could screen for smoking and add more time to the appointment to deliver the 5A's; we could explore and address billing concerns). With recent health care reform, we may also identify other system barriers that need to be addressed. Possible tailored interventions for PLWH/A could address clients' isolation and provide social support for quitting smoking in new ways (e.g., by virtual cessation support groups) and building on existing service systems. We could also develop and test an intervention in which a person calls on behalf of CAREAssist to ask about smoking and refer to services, and assess the cost-effectiveness of this approach.

Results from both these short-term and long-term interventions could help inform approaches for other ADAP programs in the country, as well as other populations living with chronic conditions and co-morbidities.